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**Improved access to health care and self-management of long-term and disabling conditions including end-of-life care: a corpus of published work incorporating evidence appraisals and critical approaches to public health.**



Charlotte Wilson

**This dissertation is submitted for the degree of Doctor of**

**Philosophy**

**February, 2019**

## **Declaration**

This thesis has not been submitted in support of an application for another degree at this or any other university. It is the result of my own work and includes nothing that is the outcome of work done in collaboration except where specifically indicated.

Charlotte Wilson, BSc (Hon), MA (Econ), PGCE

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## **Abstract**

This thesis synthesises and evaluates the evidence base of key areas in public health and palliative care research. The author's published works are integrated throughout and critical discussion of methodological and theoretical aspects are expanded. The principal aims include optimisation of self-management of long-term conditions and the improvement of access to healthcare for marginalised groups. It also specifically examines improved quality of care through the delivery of appropriate communication skills, and the identification of reliable and valid outcomes for people affected with illness or disability. Broader aims include improved patient satisfaction with health care services and an evaluation of systemic aspects of care and patient, public involvement in research.

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## **List of Abbreviations and Acronyms**

BBN: Breaking Bad News

BCT: Behavioural Change Training

BMJ: British Medical Journal

CHD: Coronary Heart Disease

CKD: Chronic Kidney Disease

COPD: Chronic Obstructive Pulmonary Disease

CRUK: Cancer Research UK

CST: Communication Skills Training

CVD: Coronary Vascular Disease

DNPS: District Nursing Psychological Support Study

DoH: Department of Health

EAPC: European Association of Palliative Care

EBM: Evidence Based Medicine

ESRC: Economic Social Research Council

EJON: European Journal of Oncology Nursing

EGOS: Erasmus GBS Outcome Score

EME: Efficacy and Mechanism Evaluation

FSS: Fatigue Severity Scale

GBS: Guillain Barre Syndrome

GCP: Good Clinical Practice

GDPR: General Data Protection Regulations

GNI: Gross National Income

GP: General Practitioner

HADS: Hospital Anxiety and Depression Scale

HS and DR: Health Services and Delivery Research

HTA; Health Technology Assessment

IFS: Institute of Fiscal Studies

IGOS: International Guillain Barre Syndrome Outcome Study

ILM: Institute of Leadership and Management

LTC: Long-Term Conditions

MDT: Multi-disciplinary Team

MMS: Multi-media message service

MRC: Medical Research Council

NHS: National Health Service

NICE: National Institute of Clinical Excellence

NIHR: National Institute of Health Research

NIHR CLAHRC: National Institute of Health Research, Collaboration of Leadership in Applied Health Research and Care

NMC: Nursing and Midwifery Council

NRES: National Research Ethics Service

ODA: Official Development Assistance

ODSS: Overall Disability Sum Score

PPI: Patient and Public Involvement

PPIE: Patient and Public Involvement and Engagement

PRISMS: Practical systematic Review of Self-Management Support for long-term conditions

PROMS: Patient Reported Outcome Measures

RCGP: Royal College of General Practitioners

RCN: Royal College of Nursing

RCP: Royal College of Physicians

RCT: Randomised Controlled Trial

REF: Research and Excellence Framework

SAGE and THYME: **S**etting, **A**sk, **G**ather, **E**mpathy; **T**alk, **H**elp, **Y**ou, **M**e, **E**nd.

SMBG: Self-Monitoring of Blood Glucose

SMS: Short Message Service

SPIKES: **S**etting Up the Interview, Assessing the Patients **P**erception, Obtaining the Patients **I**nvitation, Giving **K**nowledge and Information to the Patient, Addressing Patients **E**motions with **E**mpathic Responses, **S**trategy and **S**ummary

QoF: Quality and Outcomes Framework

WHO: World Health Organisation

1. Improved access to health care and self-management of long-term and disabling conditions including end-of-life care: a corpus of published work incorporating evidence appraisals and critical approaches to public health.

## 2. Aims

- To summarise each publication submitted outlining their interrelationship
- To demonstrate how my work has contributed to the relevant research fields
- To provide a critical review of the current state of knowledge and research in these fields
- To demonstrate how my work has contributed to these areas and made an impact in terms of the standing of journals and the reception of the publications in citations and reviews

### 3a. Biography

I was awarded a first-class BSc (Hon) in Social Sciences and an MA (Econ) Sociology and Research, followed by a PGCE in Higher Education and a Postgraduate Certificate in Research Management (Institute of Leadership and Management, ILM Level 5). After my role as a tutor at Leeds Metropolitan University, I joined the University of Manchester as a researcher investigating the use of complementary therapies in cancer care, followed by a population level study of differential Hospice at Home referral rates. I developed further interests in the optimisation of self-management in long-term conditions, and application of PPI (Patient and Public Involvement). My work with a local Breathe Easy support group (British Lung Foundation), strengthened community engagement and enabled instrument design; particularly the use of conjoint scenarios to measure patient preference and experience of symptom clusters in chronic obstructive pulmonary disease (COPD). I also worked with the Guillain Barre Syndrome (GBS) Support Group and research physiotherapist to conduct a national survey assessing physical functioning in the post-acute phase of GBS.

The next phase of work was on a National Institute of Health Research, Collaboration of Leadership in Applied Health Research and Care (NIHR CLAHRC) Programme grant. I conducted and published a systematic review on effective self-management and access to healthcare for ethnic minority groups living with diabetes mellitus. I then led a paper on patient satisfaction with follow-up services in colo-rectal cancer and developed a bid on psychosocial aspects of chronic pain management. In the following phase, I reviewed the appropriateness of referrals to nephrology services using expert panel methodology and assessed the feasibility of referral options for patients with chronic kidney disease (CKD 3-4). Finally, I conducted a pilot study to

improve the psychological support of patients with advanced cancer via delivery of communication skills to District Nurses.

In 2012, I joined the NIHR Research Design Service based at Queen Mary University London, Centre for Primary Care and Public Health. I advised investigators on research design for bids to medical charities and NIHR funding streams. I gained extensive knowledge of pragmatic trial design and cluster trial methodology as well as experience as a reviewer for the NIHR Health Services and Delivery stream. I published a book review (Wilson, 2013) and continued my interests in professional communication by teaching at Bart's Medical School; Breaking Bad News, Difficult Conversations in Womens' Health, Educational Practice (MBBS programme). In 2017, I joined the University of Cumbria, providing academic support to students and teaching Academic Skills, whilst leading an educational research project. In 2019, I was appointed as a Senior Research Methodologist specialising in PPI at Newcastle University for the NIHR Research Design Service where I currently work.

Throughout 2006-2012, I reviewed for the European Journal of Oncology Nursing (EJON), the Journal of Nursing Education in Practice, Palliative Medicine, and Health and Social Care in the Community. In 2013 and 2019, I received a Certificate in Reviewing Excellence from EJON and remain an active reviewer for this journal as well as the Journal of Nursing Education in Practice. This has developed my academic writing and skills of critique in assessing the research question, ethics, suitability of methods, thoroughness of reporting, accuracy of results, and interpretation of results. I have therefore gained experience of the peer review process as both an author and reviewer in several sub-disciplines of applied health research.

### 3b Author identification

Table 1 Author identification	
ORCID ID	<a href="https://orcid.org/0000-0002-7523-2987">https://orcid.org/0000-0002-7523-2987</a>
Scopus Author ID	<a href="https://orcid.org/0000-0002-7523-2987">55477617900</a>
Research Gate	<a href="https://www.researchgate.net/profile/Charlotte_Wilson7">https://www.researchgate.net/profile/Charlotte_Wilson7</a>
Google Scholar	<a href="https://scholar.google.co.uk/citations?hl=en&amp;user=gtAbDqcAAA_AJ">https://scholar.google.co.uk/citations?hl=en&amp;user=gtAbDqcAAA_AJ</a>

#### 4. Research agendas

In this PhD, I discuss my research agendas and their inter-relationships. I also evaluate the context of this work in terms of broader research contexts; public health, population health, statistics, evidence-based medicine, critical health research, PPI and ethics. Whilst I have brought distinct contributions to the publications from social science and social research (Table 2); overall however, I would identify primarily as an applied health researcher within the NIHR mandate for research, where the requirements of funding bodies have been a main priority.

Figure 1 is a de novo diagram outlining my main over-arching research agendas. Emerging research agendas are those that developed as the research progressed whereas the main agendas were planned from the outset. For instance, as a teacher and researcher, I developed a strong interest in the identification of training needs and development and evaluation of educational programmes. This became an emerging theme throughout my published work. Specifically, the need for improved intercultural communication in the systematic review; effective communication in supportive palliative care (district nursing psychological support study) and complementary therapist training in communication skills. Patient and Public Involvement sits as a crosscutting, though separate research related activity.

4. Figure 1: Overview of over-arching and emerging research agendas, Wilson, C. (2019)

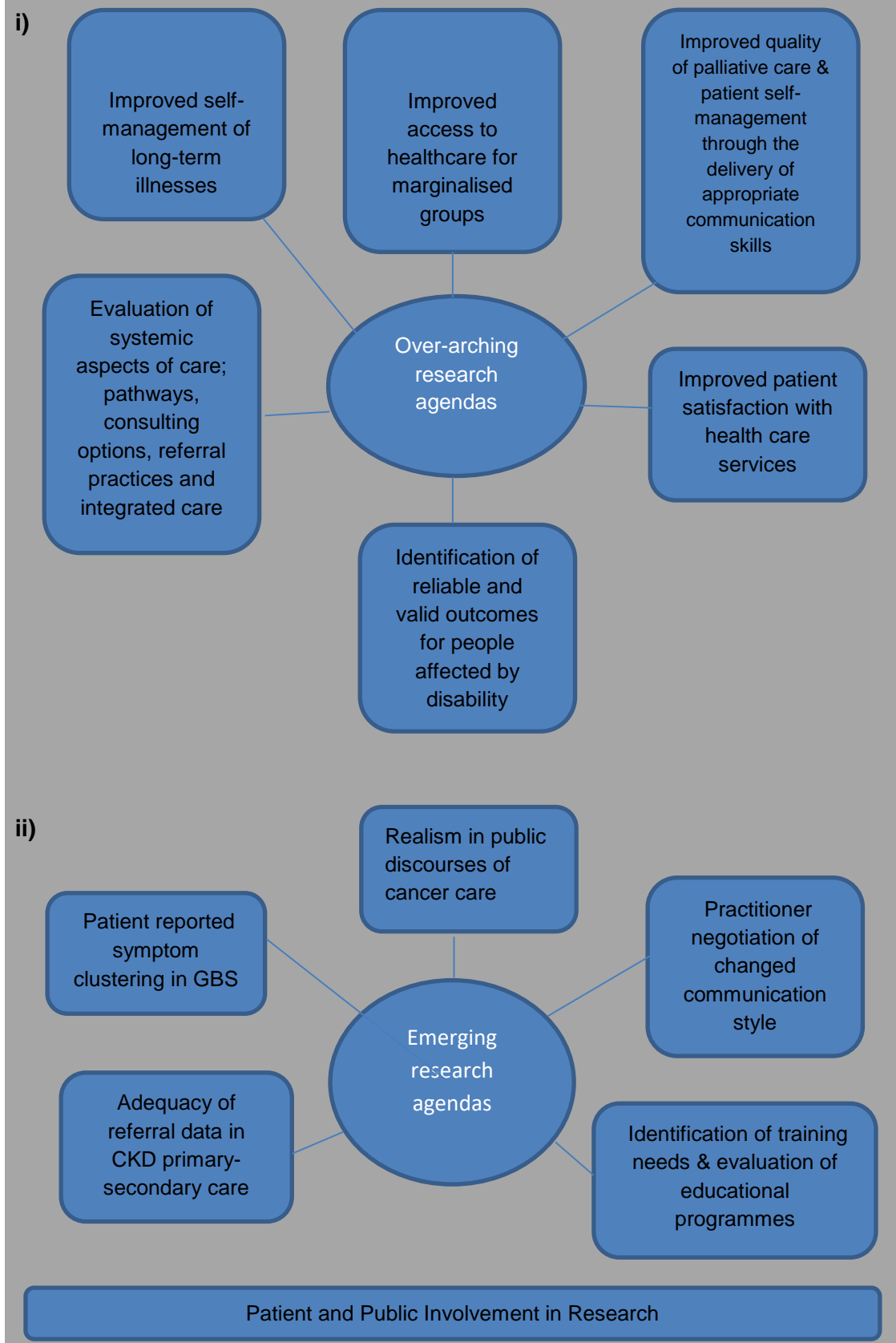




Table 2 outlines the corresponding aims of my research portfolio and the publications that relate to each aim. The PPI work informed the research design of the published material.

<b>4. Table 2; Research agendas</b>	
<b>Aims</b>	<b>Publications</b>
To optimise self-management of long-term illnesses	Systematic Review: Diabetes  Referral and Management Options for patients with CKD.
To improve access to healthcare for marginalised groups	Systematic Review: Diabetes  National Survey: Guillain Barre Syndrome.  Exploring differences in referrals to a hospice at home service.
To improve quality of palliative care through the delivery of appropriate communication skills	District Nursing of Palliative Care in the Community. i) Improving communication with palliative care patients at home, Tool evaluation ii) Breaking Bad News about transitions to dying; role of DN iii) Challenges of Supporting patients in the home, qualitative exploration.
To improve patient satisfaction with health care services	Colo-rectal cancer follow-up: Patient satisfaction and amenability to follow-up
To identify reliable and valid outcomes for people affected by disability	National Survey: Guillain Barre Syndrome: What constitutes a good recovery in post-acute GBS?
To evaluate systemic aspects of care; pathways, consulting options, referral practices and integrated care	Referral and Management Options for patients with CKD  Complementary Therapies in Cancer
To further patient and public involvement in research (PPI)	<i>Extensive consultation</i> <i>Unpublished</i>

## 5. Publication overview

Section 5 Table 3, presents an overview of publications and my distinct contributions.

<b>Table 3: Publication overview</b>				
<b>Author</b>	<b>Title</b>	<b>Group</b>	<b>Methodology</b>	<b>CW IP Contribution</b>
First author	Patient access to healthcare services and optimisation of self-management for ethnic minority populations living with diabetes: a systematic review	LTCs: Diabetes Mellitus Type 2 Ethnic minorities	Systematic Review Secondary data  Analysis; Critical Appraisal of Evidence	-Advocated a multi-dimensional model of access to include broader socio-cultural factors beyond disease related outcomes, in heterogeneous international settings -Rationalised methodological approach that included effectiveness as well as efficacy - Devised consistent scoring system, allowing an assessment of quality across study type -Led extraction, synthesis and appraisal of mixed evidence base (study designs) to form discussion, conclusion and recommendations for practice - Took a critical approach to concept of ethnicity and its relationship with socio-economic status.
First author	Referral and management options for patients with CKD; perspectives of patients, generalists and specialists	LTCs: CKD 3-4  Patients 18+ Practitioners; general, specialists	Mixed methods Patient Interviews at home and telephone Practitioner interviews via telephone Analysis; Thematic,	-Formulated the research question based on an earlier literature review (Guideline interpretation discrepancy) Identified and explained a key study limitation

			constant comparison	with reference to cognitive bias in formulation of 'preference' drawing on psychology research -Formulated research priority for future research based on data and literature review; the adequacy of referral data between primary and secondary care - Provided basis for future cost effectiveness work on new disease management pathways.
Lead author	Colo-rectal cancer follow up patient satisfaction and amenability to telephone after care.	Cancer Follow-up	Surveys postal	-Rationalised a conservative threshold of statistical significance given the exploratory study aims. -Took steps to assess multi-collinearity (reported and interpreted tolerance and variance inflation factors) -Questioned the discriminatory validity of satisfaction surveys and discussed reasons for this
Author	Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK	Palliative Cancer Community Socio-economic status	Population level Secondary data Statistical analyses	-Sourced all secondary data and rationalised selection of variables based on literature -Furthered inter-disciplinary understanding of an evidenced based inverse care law based on low SES in hospice at home (dissemination at

				<p>Sociology and Palliative Care conferences)</p> <ul style="list-style-type: none"> <li>- Discursive contributions; highlighting role of caregivers in meeting PC need (where uptake of hospice at home is low)</li> <li>- Highlighted ecological fallacy in interpreting study results from the population level to individuals</li> </ul>
Author	Breaking bad news about transitions to dying; A qualitative exploration of the role of the District Nurse	Palliative Community Practitioners; district nurses	Mixed methods Focus groups, surveys	<ul style="list-style-type: none"> <li>-Challenged conceptions of the Breaking Bad News model;</li> <li>- Identified an agenda for modifying SPIKES (clinical settings) to the home</li> </ul>
Author	Improving communication with palliative care cancer patients at home; A pilot study of SAGE and THYME communication skills model	Palliative Cancer Community Practitioners; district nurses	Pilot/Evaluation Mixed methods Focus groups, surveys	<ul style="list-style-type: none"> <li>-Rationalised methodological approach: focus groups (Kitzinger, 1995) and its limitations</li> <li>-Interpreted data as focus group observer/facilitator; oversaw processes of group dynamics and impact on findings</li> <li>- Identified main themes in the data and presented to steering group to improve rigour; specifically re challenge of changing communication style, and note-taking (Goffman, Presentation of Self in Everyday Life)</li> <li>-Identified an emerging research agenda to investigate how practitioners negotiate the</li> </ul>

				perceived change in their communication style to protect a naturalistic and congruent impression (wider medical, professional application) -Challenged the appropriateness of an RCT as the subsequent phase of work
First author	A Qualitative Exploration of District Nurses' Care of Patients With Advanced Cancer; Challenges of Supporting Patients at Home	Palliative Cancer Community Practitioners; district nurses	Mixed methods Focus groups, surveys Analysis: descriptive statistics, thematic content	-Adopted a critical approach to home settings based on the data - Departed from main collaborator in keeping the realism of setting thoroughly reported: volatility, conflict, complicit behaviours - Contributed to realist research agenda of analysing public discourses on community cancer care (e.g. CRUK and Macmillan campaigns) - Identified misunderstandings about pain control as an emerging and principal theme. - Provided social scientific concepts of family dynamics to inform nursing education and case management
Author	Complementary Therapies in Cancer; Patients views on their purposes and value pre and post receipt of complementary therapy – A multi-centre case study	Palliative Cancer Secondary, Tertiary, Community services	Multiple case study mixed methods interviews, survey, validated instruments, documentary analysis	-Interpreted all statistical and qualitative data for end of year report which provided basis for paper -Interpreted results in terms of sample characteristics and instrument reference documents

				-Discursive; Highlighted the ambiguous role of CT in cancer care; tensions between demands for efficacy and patient reported benefit -negotiated implications of paper with collaborators who were CT practitioners
Author	1) What constitutes a good recovery outcome in post-acute Guillain-Barre syndrome? Results of a national survey 2) Physiotherapy and Guillain-Barre Syndrome; results of a national survey	Disability Guillain-Barre Syndrome	Population level National Survey Survey, validated instruments and qualitative	-Framed the study findings in terms of poor diagnostic criteria for GBS in general (literature review) - Conceptualised symptom clustering in GBS; how fatigue interacts with perceived well-being, anxiety and depression - Data management and interpretation

## 6. Summary of Publications

I led the systematic review: *Patient access to healthcare services and optimisation of self-management for ethnic minority populations living with diabetes*. It incorporates two large aims with evidence synthesis and appraisal of data from mixed study designs so meta-analysis was not conducted. The second paper (also CW led) is similarly aimed at vascular disease management: *Referral and management options for patients with CKD; perspectives of patients, generalists and specialists*. This is primary research using both a quantitative and qualitative approach and incorporating multiple perspectives. A key finding was the inadequacy of information on referral to specialists. This provides preliminary data from generalists, specialists and patients for research into improving shared practice and ultimately assessing cost effectiveness of any new management pathways. The subsequent paper, *Colo-rectal cancer follow up: Patient satisfaction and amenability to telephone after care* (CW led), relates to patients with cancer and the potential of nurse led telephone follow-up to improve patient satisfaction. This was also a mixed methods study, though is primarily

statistical in drawing on survey data, and is part of a broader agenda to ultimately improve the cost effectiveness of service delivery.

*Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK* is similarly focused on cancer care though in terms of access to specialist palliative care. This paper is exclusively based on an analysis of secondary data. *Complementary Therapies in Cancer; Patients views on their purposes and value pre and post receipt of complementary therapy – A multi-centre case study* is a particular departure in examining the role of complementary therapies rather than medical or self-management. The publication on the role of complementary therapies in cancer care departed from the other papers and those in its field, by emphasising uncertainties and tensions within the field. It is also the only case study approach within the papers, yet continues my research into improved palliative care in cancer.

The following three papers constitute a pilot evaluation of a communication tool for District Nurses caring for patients with cancer in the community. *Improving communication with palliative care cancer patients at home; A pilot study of SAGE and THYME communication skills model*, reports the main findings based on a series of surveys and practitioner focus groups. *Breaking bad news about transitions to dying; A qualitative exploration of the role of the District Nurses*, is the paper specifically examining the role of nurses in BBN and the process of this communication. The third paper which I also led; *A Qualitative Exploration of District Nurses' Care of Patients With Advanced Cancer; Challenges of Supporting Patients at Home*, focuses on the challenges of the home setting itself and how family relationships impact on care delivery.

Finally, two papers report results from the National Survey of Guillain Barre Syndrome. This work involves an assessment of outcomes in a disabling condition, which is rare and distinct from chronic illnesses in its trajectory. *What constitutes a good recovery outcome in post-acute Guillain-Barre syndrome? Results of a national survey* reports the main results and implications for research practice. The paper *Physiotherapy and Guillain-Barre Syndrome; results of a national survey*, specifically explores these issues in relation to improved access to physiotherapy in the recovery phase.

## 7. Author contributions

As a research associate, I was responsible for all aspects of the research so contributed to the research design, data collection, analysis and all outputs. However, distinct contributions are outlined in Table 3 and some examples are discussed below. The papers are related by themes, develop methodologically and make highly significant contributions to the field.

#### a. Systematic review

In the systematic review, I led extraction, synthesis and appraisal of a mixed evidence base, and wrote the discussion, conclusion and recommendations for practice. As my systematic review was distinctively broad in scope, it drew on mixed study designs; its findings were not limited to RCTs and the narrow determination of efficacy, but also included patient reported effectiveness. I therefore identified the persistent barriers faced by ethnic minorities at all three levels of the whole systems approach and across several dimensions of access. As a social scientist, I was able to focus on social and cultural factors as well as those relating to health services. Comprehensive findings were therefore reported on health service utilisation, quality of care and adequacy of information, access interventions, health service accommodation and the role of socio-economic status and cultural aspects. Issues of self-management were appraised in terms of knowledge and understanding, trust in medical advice, self-management practices, language and treatment responsiveness.

I followed the rigorous systematic review approach, yet adapted it with justification to include evidence beyond trials due to heterogeneity of outcomes, settings and countries. This reflects the broader roots of health inequalities beyond clinical domains and supported the multi-dimensional model. I devised a *de novo* consistent scoring system, allowing an assessment of quality across study type. This allowed broad outcomes to be presented far beyond glycaemic control, which has high validity in understanding health inequalities since the antecedents of health inequalities are social, economic and political in origin. Indeed, a focus on glycaemic control or hospital utilisation alone may individualise the problem and depoliticise health inequalities. Similarly, qualitative research alone - often interviewing individuals or seeking to understand their biography - may inadvertently imply the explanation rests with individuals or personal stories, whereas good quality population research is able to identify structural patterns and trends. Section 9b expands this discussion on a triangulation of methods.

In making these methodological choices, I therefore contributed to a critical public health agenda, and challenged the operational construct of 'ethnicity' and its relationship with socio-economic status. I suggest that ethnicity and socio-economic status intersect and are likely to be inevitably confounded, particularly in terms of lived experience and our understanding of barriers to improved health equality. The emphasis on *inequalities* rather than *inequality*, is sociological and my key contribution is in understanding why some people in society will experience illness and early death because of ethnicity and material factors. The paper therefore made a major contribution to research in this field by offering a critical synthesis and appraisal of high quality evidence from social, cultural and medical domains.



#### b. Guillain-Barre Syndrome Study

In the papers on a national survey of Guillain-Barre Syndrome, I advanced the field by reporting data on a particularly large and inclusive sample of patients. I made a major contribution by hypothesising symptom clustering in GBS i.e. how fatigue interacts with perceived well-being, anxiety and depression. This emphasis is important since most of the research activity to date has focused on a narrow definition of medical recovery where the patient no longer requires hospitalisation or ventilation and an acute episode has lifted. My publications demonstrated that the F-Score for functional ability in GBS, commonly used to date (Hughes *et al.*, 1978, 2007), failed to reliably measure fatigue and led to enduring disability for patients who would benefit from physiotherapy. Prolonged disability is aggravated by reduced access to physiotherapy for vulnerable groups: children and older groups with increased morbidities.

I researched the natural history of GBS extensively and framed the study findings in terms of poor diagnostic criteria for GBS. This contributed to a UK evaluation of disease outcome measures, which has since been pursued by the IGOS: International Guillain Barre Syndrome Outcome Study (Jacobs *et al.*, 2017), though interestingly, the IGOS data has only an eighth the UK sample size of our earlier national survey. Overall, my contribution to the hypothesis, data analysis and interpretation has meant that the treatment of patients experiencing fatigue and or psychosocial symptoms could be improved through a more sensitive diagnostic approach and holistic approach to how symptoms are experienced in combination.

#### c. Communication in community palliative care

In the papers from the evaluation of the communication tool SAGE and THYME, I also added distinct progressions to palliative care research. In identifying how the training led to increased confidence and motivation for DNs to deal with psychosocial issues, it arrived at a feasible option for improved nursing-led supportive care. This departs from the emphasis in surrounding literature on medic-led communication skills, and challenges application of the Breaking Bad News model itself (Griffiths, Wilson, *et al.*, 2015). The data led me to adopt and defend a critical approach to home care settings. I departed from the main collaborator in keeping the realism of the setting thoroughly reported and un-moderated. Findings highlighted how the home could be the site of conflict, volatility and 'challenge' for district nursing; many of these factors associated with lower socio-economic status (Wilson *et al.*, 2014). Crucially, these were not just background factors, but played a role in compromising the communication of breaking bad news and palliative care as an option. This provides a contrasting evidence base to healthcare policy and cancer care discourses which tend to assume family input as benevolent

and unproblematic in patient care (CRUK and Macmillan campaigns). This therefore contributed to a realist research agenda of analysing public discourses on community cancer care which I intend to develop.

I also provided social scientific concepts of family dynamics to inform nursing education and case management. Family relationships are covered in many nursing curricula, yet as peripheral or contextual issues, and whilst DoH policy is to include family and carers in decision making wherever possible, this is assumed as a simple dynamic of jointly made effective patient centred care. The theoretical and applied body of work, which can be traced to classical authors such as Satir (1964,1972), argues quite the opposite: the self is often constructed within family role-play and massively shaped by it, in ways that may undermine autonomy.

I also identified an emerging research agenda to investigate how practitioners negotiate the perceived change in their communication style to protect a naturalistic and congruent impression. This has application to wider medical professional communication, and communication skills in general. This was very much led by the data in that nurses regarded any change to their communication style: both speech and the habit of note taking, as undermining to their presentation of self, so that any changes would only be tried with new patients. As a social scientist by background and having used a dramaturgical approach for my Masters, I found this particularly significant, since this is no superficial barrier, but following Goffman (1959), the performative work we do to preserve a consistent identity is interactionally powerful and discomfiting when compromised. The collaboration with this paper meant I was limited to discuss this in depth but the issue was included. I also made further distinct contributions to the methodological rationale, interpretation of focus group data in terms of group dynamics, identification of misunderstandings about pain control as an emerging and principal theme, as well as challenging the appropriateness of an RCT as a subsequent phase of work (Table 3). Overall, my contribution has been to advance awareness in nursing care that sensitive conversations are essential to the well-being of the dying patient.

#### d. Referral and consulting options in CKD

A further distinctive contribution was the multi-perspective review of referral and consulting options in CKD. Here, I offered a critical approach to the existing disease management pathway, questioned current views of best practice and the interpretation of clinical guidelines in practice. I formulated this research question, based on an earlier literature review that showed discrepancies in guideline interpretation. One of my contributions was in the identification of possible cognitive bias in patients' formulation of 'preference'. Section 12b reflects on broader related issues in more depth. The

measurement of perceptions, attitudes and views in health research is quite often reported without a full consideration of how these impressions are formed, and whilst the literature on cognitive psychology is not new, by bringing this into my study interpretation, (Kahneman, 2011) I was able to argue how these preferences are formed. I also made the additional contribution of formulating a future research agenda: the adequacy of referral data between primary and secondary care, and provided a basis for future cost effectiveness work on new disease management pathways.

#### e. Complementary therapies in Cancer Care

In the complementary therapies paper, my main contribution besides data collection and analyses (Table 3) was in discursive interpretation. I highlighted the ambiguous role of CT in cancer care; and tensions between demands for efficacy and patient reported benefit. Whilst presenting empirical data, I explained the results largely in terms of sample characteristics, therapeutic process effects, and in relation to a field with unresolved definitions, criteria for evidence, and ambiguities around integrative medicine itself. Whilst this offers little of concrete evidence to service commissioners in terms of recommendations, it highlights a lack of evidence and contributes to a more critical public health research field. Evidence of limited evidence is a valued form of knowledge. The problem of publication bias in health research is mainly due to the under-publication of negative or null findings, and includes an under-publication of papers making no definitive conclusions (Bax and Moons, 2011). My distinct contribution was therefore to counter this trend and contribute to the larger field of what is and what is not known about an area. A full overview of distinct contributions can be found in Table 3.

## 8. Research Agenda relationships

Figure 2 outlines the relationships between my research agendas in published work. The text in white font indicates aspects most directly experienced by patients. The text in black font indicates the research agendas arising from them.

**8. Figure 2: Research agenda relationships, Wilson, C. (2019)**

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graph TD; SI[Social Inequalities  
Socio-economic status, Ethnicity & culture, Disease Propensity, Disability, Health] --> STS[Secondary, Tertiary Services  
Specialist e.g. nephrology  
Palliative Care → Hospice at Home  
Cancer Care  
Physiotherapy]; AC[Access to Care;  
availability, uptake, acceptability, accommodation] --> MMF[Medical Management & Follow-up  
Complex cases]; SI --- R1[Research: improve access to care for marginalised groups]; AC --- R1; AC --> R2[Research: referral, consulting options]; R2 -- Referrals --> STS; STS --- R3[Research: patient amenability & satisfaction. Longer term: recurrence detection, cost equivalence]; MMF --> R3; MMF --> SSM[Supported Self-Management (80% of cases)  
Educational Interventions; lay, peer or practitioner led, digital programs]; SSM --> NTF[Nurse led Telephone follow-up]; NTF --> STS; NTF --> R4[Research: self-management efficacy, benefit, cost effectiveness, perspectives, provider communication]; SSM --- R5[Research: Health outcomes  
Mortality, Morbidity, Quality of Life, Psychosocial, carer outcomes; coping, support]; STS --- R6[Research  
Provider communication  
Evaluate outcome measures (disability)]; R6 --- R4; PPIR[Patient and Public Involvement in Research]
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The diagram illustrates research agenda relationships across several key areas:

- Social Inequalities**: Socio-economic status, Ethnicity & culture, Disease Propensity, Disability, Health.
- Access to Care**: availability, uptake, acceptability, accommodation.
- Medical Management & Follow-up**: Complex cases.
- Supported Self-Management (80% of cases)**: Educational Interventions; lay, peer or practitioner led, digital programs.
- Secondary, Tertiary Services**: Specialist e.g. nephrology, Palliative Care → Hospice at Home, Cancer Care, Physiotherapy.
- Nurse led Telephone follow-up**.
- Research**:
  - improve access to care for marginalised groups (linked to Social Inequalities and Access to Care).
  - referral, consulting options (linked to Access to Care and Referrals).
  - patient amenability & satisfaction. Longer term: recurrence detection, cost equivalence (linked to Secondary, Tertiary Services and Medical Management & Follow-up).
  - self-management efficacy, benefit, cost effectiveness, perspectives, provider communication (linked to Nurse led Telephone follow-up and Research Provider communication).
  - Health outcomes: Mortality, Morbidity, Quality of Life, Psychosocial, carer outcomes; coping, support (linked to Supported Self-Management).
  - Provider communication, Evaluate outcome measures (disability) (linked to Secondary, Tertiary Services).
- Referrals**: A central flow from Medical Management & Follow-up to Secondary, Tertiary Services.
- Patient and Public Involvement in Research**: A foundational element at the bottom.

#### a. Social Inequalities

Factors or group characteristics of social inequality drove the research agenda to improve access to care for marginalised groups and an exploration of the several dimensions of availability, uptake, acceptability and accommodation. These are relevant both to medically managed and self-managed cases, and ultimately result in inequalities of outcome; morbidity and mortality, though also, secondary or patient reported outcomes such as quality of life, psych-social outcomes (anxiety, depression, mood disturbance, coping), and impact on carers. These are appraised in depth within the broad systematic review. They are also linked to key discussions in papers evaluating provider communication and the evaluation of disease specific outcome measures. As shown by figure 2, social inequalities affecting health are themes within papers on CKD referral, communication in palliative care, hospice at home and access to physiotherapy in GBS.

#### b. Medical management and follow-up

Medical management and follow-up makes reference to the management of complex cases and follow-up of patients in clinics and so relates to health care utilisation as well as patient level factors. The adequacy and appropriateness of referrals between primary and secondary care and to other specialist services is investigated in the CKD consulting options paper. This agenda in turn is dependent on access factors e.g., patient acceptability of options for telephone review, or differences in availability by region or trust, so has the function of applying the broad review aims; access to care and optimisation of self-management to a narrower focus on CKD 3-4 health service management. The question of differential access, and possibly referral to palliative care and palliative home care in particular, is also highlighted by the Hospice at Home paper. The paper on physiotherapy in GBS highlights how a better appraisal of need may improve referrals to physiotherapy for rehabilitation. Overall, both access to care and improved referrals between services are main agendas of these papers.

#### c. Nurse-led follow-up

Related to the aim of improving supported self-management is the agenda of investigating nurse-led telephone follow-up: a theme explored in the colorectal cancer follow up paper. The research constructs emerging from this and seen in the papers impact legacy have ranged from an assessment of patients' amenability and service satisfaction to improved, long term detection rates and ultimately cost effectiveness compared to usual care. This itself is a consulting option that was also explored in the CKD referrals paper so serves as a more in-depth investigation in another disease group and service. Whilst

the aim of a cancer clinic will always be in part, the detection of recurrent disease – rather than the management of existing disease, the research agenda of exploring patients' perspectives and responsiveness to a more cost effective or cost equivalent service is the same across clinical areas. Overall, nurse-led telephone up in colorectal cancer as an agenda, relates to the CKD paper on consulting options and more broadly to provider communication and future evaluation of outcomes

#### d. Provider communication

Provider communication is also a key finding within the colorectal paper, the papers on community cancer care (SAGE and THYME), and results within the systematic review; the latter including intercultural communication. Understood chronologically, communication as a barrier to effective self-management in vascular disease was my original focus, which then developed into the other areas of follow up in cancer care and communication in end-of-life.

### 9. Research Agenda Contexts

#### a. Public Health Research

The health research I have produced is driven by a public research agenda outlined in the Cooksey Report (Cooksey, 2006). This review set out a mandate and invested funds in *applied* health research: research with the potential to implement clinically significant change or improvements in health services and patient outcomes. The research involves collaborations between academics, clinical partners and increasingly patient and public perspectives (INVOLVE, 2018). The improvement of access to treatment, clinical effectiveness and cost effectiveness is central to this research agenda (Smith *et al.*, 2017). However, public health encompasses much broader aspects relating to the prevention of disease itself; air pollution (Department of Health, 2013), nutrition (Tedstone *et al.*, 2015), sedentary behaviours or physical inactivity (Biddle, 2010; Digital NHS, 2018b), alcohol consumption (Rehm *et al.*, 2009), smoking cessation (Foster *et al.*, 2007) and sexual health (Department of Health, 2013). Public understanding of these areas, either framed as views, perceptions, attitudes, health literacies etc. shape behavioural outcomes. These behavioural factors elevate the risk of and incidence of disease. Event factors as seen in an evaluation of the Olympic Games for its impact on population activity (DoH, 2013) and local residents (Thompson *et al.*, 2015), or the implications of Grenfell 2017 for public safety and social equality, are also public health agendas.

Overall, paradigms beyond the medical model emphasise that public health issues affecting individuals or groups arise from socio-economic contexts (Greenhalgh *et al.*, 2015). Whilst there are global burdens of disease and

national responses to health interact, as a developed country with advanced infrastructure the UK's agendas are distinct from the global public health agendas of less developed countries, and have commonalities with European, Westernised societies (Health *et al.*, 2009). The question of what a public health system should aim to achieve is fundamental, and distinguishable from a paradigm that sets its remit on what it can achieve given current resourcing; an aim to improve health is broader than the medical remit of treating sickness, yet the control of disease is better placed much earlier within primary prevention (Guilliford, 2017).

#### b. Population health

A key feature of public health research and my research to date is population level data analyses. Findings of statistically significant correlations at the population level are interpreted to make inferences about individuals, groups and clinical settings. An awareness of the ecological fallacy, which I discussed in Campbell *et al.*, (2010) is important here in avoiding the conflation of levels of inquiry and overlooking the validity of individual experience, group effects/dynamics and the lived experiences of patients or practitioners. As such, the use of mixed methods, where quantitative and qualitative approaches are designed to answer specific research questions, has added reliability and validity (O'Cathain, Murphy and Nicholl, 2007) to my research projects.

#### c. Statistics

Statistical significance alone is a decontextualized research finding. It is important to interpret statistical significance (the p-value) in conjunction with the test assumptions, confidence intervals and descriptive data, whilst appreciating that the boundaries of p-value significance may shift depending on the research hypothesis (Benjamin *et al.*, 2017). In a controlled trial, the effect of a treatment (effect size), with its relative risk, provides indication of its effect beyond chance (Leung, 2001). This balance between statistical and clinical significance in interpretation of intervention research, and the methodological training to make inferences from population data is crucial to the field, and has formed part of my training to date, particularly as evidenced by the systematic review and population level studies.

Whilst these methodological approaches are at the peak of the classic evidential pyramid in terms of quality of evidence, there is a strong argument that this hierarchy should be questioned (Greenhalgh, Thorne and Malterud, 2018) (Greenhalgh, Thorne and Malterud, 2018). The qualitative approaches used in my papers have elicited valuable findings to population health albeit with different epistemology and methodologies. It is also worth acknowledging that the very basis of the p-value itself has been debated and seen as an



overly reified in applied statistics (Baker, 2016; Greenland *et al.*, 2016; Wasserstein and Lazar, 2016).

#### d. Evidence-based Medicine

Public health research has mainly evolved in parallel with evidence-based medicine (EBM), classically outlined by Sackett, *et.al.* (1991). The search for an empirical evidence base to medical decision-making and efficacy in terms of trials was envisaged to sit aside clinical experience based knowledge (Greenhalgh, 1999). This paradigm is still evident in the most influential public health bodies, NICE, DoH and NIHR HTA and EME (Health Technology Assessment, Efficacy and Mechanism Evaluation). A critical approach to EBM includes the following concerns. A commentary in the RCGP (Lipman, In Royal College of General Practitioners, 2005) argues that an over-reliance on guidelines works against the medical judgment of particularly primary care physicians. The language of certainty typically found in clinical guidelines masks the fact that evidence is often expert opinion based, uncritical of methodology and lacking in transparency. There is a further concern that as clinicians lack training in clinical epidemiology, non-clinicians overly interpret EBM.

These concerns can imply that the interpretive, experiential aspects of clinical decision-making are more reliable than *evidence*, yet there are human limitations in practice based decision-making such as in-attentional blindness and pattern-matching deficits to consider (Al-Moteri *et al.*, 2018). It is also worth acknowledging that EBM was never intended to undermine clinical expertise and that evidence is broader than RCTs and meta-analyses, including the views of patients (Sackett *et al.*, 1996). There is a case that a post-guidelines era may involve more sophisticated context based knowledge tools and a greater openness to case studies, multiple options and multiple actions including user centred designs (Elwyn, Wieringa and Greenhalgh, 2016). There remains, however, an enduring agenda to synthesise evidence and determine efficacy through controlled experimental study. The art and the science of medical knowledge may be conceived as either irreconcilable or epistemologically different. There is a recognition of this issue in public health research with developments such as pragmatic trial designs for complex interventions (Ferguson and Fiore, 2017), exploratory trials (Carlisle, Federico and Kimmelman, 2018) and an array of qualitative methodologies including case studies (O’Cathain, Murphy and Nicholl, 2007).

#### e. Critical Health Research

A research agenda driven by a governmental mandate to improve NHS efficiency and reduce costs may limit a critical research agenda, and evidence based research itself is a driver for reducing uncertainty (Engebretsen *et al.*, 2016) and promoting Medicine and Nursing as compliance led professions.

As medical management is directed by national clinical guidelines and trust level protocols, the space for discretionary clinical decision-making and questioning of practice can seem narrow (Greenhalgh, 2018). However, there is a critical agenda to evaluate policy, partly enabled by research active clinical staff and health researchers with backgrounds in social science, economics, psychology, and business – enabling a clinical ‘outsider’ or ‘inside outsider’ (Hoffman, 2011) perspective, perhaps freed from the main duties of treating patients.

A major issue is the question of over-medicalisation or over-diagnosis and treatment of illness. This relates to my publications on vascular health (Wilson *et al.*, 2012; Wilson *et al.*, 2015). Since 2004, Primary Care clinicians have been incentivised to detect, monitor and prescribe medications, to meet the Quality and Outcomes Framework (QoF). As such, medication prescriptions have tripled, hospitalisations for adverse reactions increased, and arguably, patients’ preferences marginalised (Francis, 2018). For example, some conditions such as mild hypertension, prescribed medication may only confer negligible benefit and be experienced as an unacceptably high side effect burden by patients. The evidence base for pre-diabetes may also lead to premature treatment with null positive outcome (Kivimäki and Tabák, 2018).

Overall, a recent review found ‘no definitive evidence that QoF has had any significant effect on emergency admissions or population health or that it is an effective method for reducing inequalities in health or healthcare’ (Forbes *et al.*, 2016). Significantly, Scotland replaced QoF with a patient centred Realistic Medicine model in 2017, which is yet to be evaluated (Christie, 2016). Much of the critical research in health can still be incorporated within the ‘whole systems’ or social ecology approach as it works to improve current systems, whereas the most critical public health agenda challenges the structural determinants of health and underlying politics (Greenhalgh, 2009). Overall, whilst adding an invaluable voice, the critical public health agenda is likely to remain at the periphery of the public health domain with limited potential to directly effect change.

#### 9f. Patient and Public Involvement in Research (PPI)

Patient and Public Involvement in Research in health research refers to ‘the involvement of patients and carers in the research process; not as study participants, but as consultants, collaborators or leaders in the design, conduct or dissemination of research’ (Hayes, Buckland and Tarpey, 2012; INVOLVE, 2018). The goals of this agenda are to empower service-users and improve the quality of research design. In applied public health research, the focus on patient reported outcomes means there is potential for lay involvement, and many models of PPI have developed, including varying levels of participation – from consultation such as advisory group membership,

to collaboration; such as lay-led activities. Some service-users and researchers have found PPI both beneficial and rewarding (Rhodes *et al.*, 2002), (Entwistle *et al.* 1998).

### Co-production in PPI

It is important to give co-production of research a particular focus since it represents a paradigm shift in challenging the traditional model of researcher as leader of research. Its principle is to make public representatives equal partners in research at all or most stages of a project and to underpin activities with the core values of reciprocity, inclusiveness, knowledge sharing and relationship sustainability (INVOLVE, 2019). This can be usefully contrasted to the traditional model of research which is done *to* rather than *with* patients. Having been a subject of a clinical explanatory trial myself I can say the experience very much follows the sequence; *this is what is going to happen, at these times and venues, here is the trial participation sheet, any questions, sign the consent form*. There is here an issue of being largely passive in the research process, but also an issue of what kind of research is produced as a result.

There are many examples of co-production having positive outcomes. A recent example is the involvement of mental health service users as lead analysts of qualitative research data, and the development of a best practice framework (Jennings, *et al.* 2018). In a further study of parents' experiences of stillbirth and bereavement, creative workshops and remembrance activities brought clinicians, parents and researchers together as partners in working towards prevention of stillbirth and improved bereavement care (Rice, Nuzum, & O'Connell *et al.*, 2019). Finally, a participatory research study, involved engaging elderly people in priority setting, interviewing and data analysis for environmental research within the community (Mey, & van Hoven, 2019). Here, the non-lay researcher had a re-defined role as trainer and facilitator mindful of managing the evolving expectations of lay co-researchers.

### Challenges of realising co-production

There are unresolved tensions within co-productive approaches. As Rose and Kalathil (2019) suggest, in terms of mental health research, the practical use of co-production has merely replicated the privileging of reason so that service user voices are still marginalised.

In my role as an NIHR PPIE (Patient & Public Involvement and Engagement) Advisor, I find there is an increased emphasis on the skill utilisation and training needs of public contributors to ensure they are relevant to the project. It is reasonable in the sense that the public feel equipped to contribute and their involvement is meaningful. However, there is a risk that this breeds a new credentialism based not on lived experience of an illness, service

experience or caring responsibilities but other forms of educational capital such as completion of a PPI training course, employment based experience of community engagement and other higher level qualifications that are deemed to make a public contributor more suitable. In the context of social inequalities, those without these forms of cultural capital may all too easily be deemed unsuitable rather than given a voice to take part, therefore unwittingly furthering health inequalities.

If this is related to Bourdieu's (1979) original concept of cultural capital, it can be argued that the very inclination towards voluntary participation and interest in educational advancement is part of a specifically middle-class sensibility. Deficits in economic capital can be remedied by payments for time and travel expenses, but what is more problematic is a failure to resonate with the values of public contributors where they differ from bourgeoisie sensibilities, as classically understood. It is these entrenched barriers to engagement that make creative and inclusive co-production and participatory research approaches all the more necessary. The barriers to healthcare and research involvement in the UK and developed countries is challenging; yet what is most challenging is community engagement in research globally. Global health research has been treated as a specialist area but since 2015, the UK aid strategy (HM Treasury, 2015) has been to spend 0.7% of gross national income (GNI) on official development assistance (ODA), leading to a UK NIHR commitment to global health research. In countries facing lack of basic healthcare such as hydration, medication or sanitation, it is clear that community engagement strategies need to be appropriate and specific to setting.

### Conceptual understandings of PPI

A schema for understanding PPI related to my experience is found in the social constructivism of Moscovici (1976). Perhaps the most apparent view is that in writing plain English summaries and documents for public audiences in consultation exercises, I have merely made the information accessible. However, for Moscovici, it is less about relaying information than collectively arriving at a common sense notion of it. The researcher anticipates what the public can comprehend and the cycle continues. It is a relational process of making science knowable. The counter argument is that where I have experienced many instances of patients' priorities being to discuss their medication or topics with seemingly low relevance to the researcher, the two sets of priorities are rarely reconciled and can remain contradictory.

The affective domain is also relevant. It is possible to identify feelings of emotion experienced by public members in PPI exercises (often support meetings or discussion group formats), as well as researcher experiences of their own emotions. Yet the relationship between the two are rarely

acknowledged. One approach by Deleuze and Guattari (2004), emphasises the relational aspects of affective interchange which is not so much the personal experience of emotion, but an intense, embodied and unconscious interplay resistant to language. These process issues remain outside the official discourse on PPI, yet are embedded within the researcher and public's experiences of the involvement exercises.

### Summary of PPI

Overall, it is hard to argue against the democratisation of the research process in principle. However, aside from the empowerment discourse and instances of good practice, there is an argument that PPI does not necessarily improve the quality of research (Hogg, 2007; Cook, 2012), or may mainly do so only in the early stages (Varkonvi-Sep, 2017). This is largely dependent on the research study, its outcomes and relative success in engaging service-users. As a Research Design Advisor, I found that most investigators struggled to rationalise and develop PPI. This is consistent with evidence that lay consultation is poorly understood and at times tokenistic (Beresford, 2009), and there seems to be little acceptance of PPI as output in academic departments or monitoring of its quality. There are developments to strengthen the rigour of PPI reporting (Brett *et.al.* 2017). However, an understanding of its impact and underlying contradictions is needed (Hayes, Buckland and Tarpey, 2012) (Snape *et al.*, 2014). As Figures 1 and 2. demonstrate, PPI sits as a separate research related activity. This is necessarily the case since ethical approval is not sought for this work and therefore publication potential is possible though limited.

### 9g. Ethical considerations

I prepared an ethics application for all the studies that led to publications including NRes, the National Research Ethics Service and University Ethics Committees. This includes preparation of the research protocol, all study documentation and a careful justification of all design issues and their consequences. Every stage of research involves ethical considerations. Having relationships with the stakeholders of research – quite often fairly personal interactions – makes the ethical responsibility of designing the research, from considerations ranging from sample size (Sim and Lewis, 2012), to survey respondent burden or choice of venue for a dissemination event, all the more relevant. This is because, whilst the field of ethics is large and complex, the applied theoretical approach, informed by phenomenology of Levinas (1969) suggests that it is in this intimacy of encountering the other, where ethical responsibility arises. This is supra organisational and policy driven as it relates to broader humanistic philosophy. The ethical conduct of research essentially protects the welfare of people from a purely scientific drive for knowledge which could cause harm and is outlined in the UK Policy

Framework for Health and Social Care Research (2018) and Caldicott principles (2013). I have maintained GCP, Good Clinical Practice certification throughout my research career, in order to meet Research governance requirements and to conduct ethical research within clinical settings. I have also kept up to date with data regulation training; most recently the General Data Protection Regulations (2018).

## 10. Contributions to research fields

This section aims to demonstrate how my work has contributed to relevant research fields and builds towards a critical review of the current state of knowledge.

### a. Self-management of long-term conditions

The effective management of long-term or chronic conditions is a key priority for public health. Chronicity as a long-term condition is defined as a disease lasting over three months duration, and progressive, non-curative in trajectory; treatment aims to slow disease progression and improve quality of life and health related outcomes for patients (National Institute of Clinical Excellence, NICE 2016, 2018). As this definition is based on a disease centred medical model, there is some evidence that the public prefer the term *long-term conditions* LTCs (INVOLVE, 2018). Also, to *self-manage, cope or live-well* incorporates the patient's psychosocial as well as physical world and the support given by carers (Morgan *et al.*, 2017). There are therefore several discourses relating to how people live with long-term illness, often either predominantly in the medical or patient centred models.

The major long-term vascular conditions affecting UK populations are coronary heart disease (CHD), diabetes mellitus type 2 (lifestyle-related), CKD and stroke: all of which are associated with hypertension and or obesity. COPD, arthritis and dementia are also long-term diseases increasing in prevalence (Naylor *et al.*, 2012; S. *et al.*, 2014; The Academy of Medical Sciences, 2018). As treatment outcomes have improved in many areas of oncology, people are living longer with cancer and managing the longer-term implications of the disease (Broggio *et al.*, 2017). The reduction in mortality due to improved treatment of long-term illness has seen an increase in years an average patient can expect to experience morbidity. The secular trend of an ageing population is a major contextual factor, as well as rising childhood obesity (Digital NHS, 2018b). A large proportion of patients have co-morbidities, and increasingly so in the under 65s, and deprived groups, as well as older age populations (Barnett *et al.*, 2012). Co-morbidities include mental health, triggering a policy agenda for health care services to adapt to trend and pace of change (Kings Fund, 2013).

The Kaiser Permanente Triangle conceptualises appropriate NHS and social care management of people with LTCs (DoH, 2005). Significantly, a relatively small proportion of people with long-term conditions require case management. Patients themselves with appropriate medical follow-up and review can manage the vast majority of conditions (70-80%) of cases. It is estimated that for non-complex cases, patients typically spend 4 hours a year with a health care professional, compared to 8.756 hours managing themselves or with carers and family (NHS, 2012). It is reasonable to hypothesise that a person's ability to self-manage may be more influential in their health outcomes than their experience within the clinic.

A principle rationale for optimising self-management is to reduce the economic burden on the NHS. In 2009, for diabetes and the treatment of associated complications, the estimated cost was 9 billion pounds or 10% of the overall, national budget (Khunti *et.al* 2009 In Wilson, C. 2012). In 2014, total costs of LTC management were estimated at 70% of the budget (15 million people, DoH, 2012). A further publication estimates 26 million people have at least one LTC, with the number experiencing two or more set to increase from 1.9 million to 2.9 million in 2018, constituting a 5 billion annual spend increase (NHS, 2012).

The evidence on projected epidemiology of disease is mixed (DoH, 2012). However, the political implications are that with cuts to the social care budget and no increase in annual NHS budgets beyond 1%, the costs are likely to escalate in real terms (Charlesworth *et al.*, 2018). This will result in probable deficits to the quality of health and social care. This recent IFS report shows that health costs as a proportion of GDP have increased annually since the 1960s; to maintain the NHS and social care system at today's level would mean a minimum 3.3% annual spend increase until 2030. There is also a case for including more prevalent disease groups; dementia (Digital NHS, 2018a) and frailty within the LTC bracket (Davies *et.al.* 2015), with resulting higher costs for geriatric groups. As well as high service utilisation cost in primary care, increased treatment costs associated with complications, acute episodes and hospitalisations, poorly managed conditions are one of the largest proportions of the NHS budget (Steventon *et al.*, 2018). A broader view also highlights how absenteeism from work due to LTCs such as heart failure and diabetic macular oedema results in losses to earnings, work efficiency and longer term career prospects (Bajorek, Hind and Bevan, 2016).

A second and related rationale of reducing the progression and impact of disease is to empower patients and carers to self-manage via educational interventions. This patient centred approach, has informed my research agenda investigating the educational needs of patients, their views on consulting options and quality of care. The evaluation of educational interventions also speaks to this agenda in terms of understanding the

effectiveness of an intervention or its efficacy (of a RCT), and its cost-effectiveness. The perspectives of health care professionals (GPs, specialists, nurses, nurse specialists, district nurses, health service commissioners) in intervention design and evaluation, are also part of the research agenda to decrease the burden of disease in population health (Wilson *et al.*, 2015).

b. Improved access to healthcare for marginalised groups

As the NHS in the UK is free at the point of access, it may appear that the healthcare system is accessible to everyone. Whilst this is the case in principle, there are enduring problems of material inequality at regional and national population levels, both in terms of developing diseases and uptake of healthcare and treatment outcomes, including mortality (Gulliford, 2017). The systematic review of interventions to optimise patient self-management and access to services (Wilson *et al.*, 2012), aimed to address this problem for South Asian groups who have both a higher incidence of vascular disease and a lower access to services. The hospice at home population level study (Campbell *et al.*, 2010) had similar aims in terms of the lower access to home based palliative care in lower socio-economic groups. This was driven by the same evidence base for palliative care in general. In conducting the national study of Guillain Barre Syndrome (Davidson *et al.*, 2009), the broader aim was similarly to improve access to physiotherapy for people experiencing post-acute disability.

c. End of Life and Palliative Care

Limited access to palliative care is an issue of social inequality in common with generic care, and one I investigated in relation to hospice at home services (Campbell *et al.*, 2010). The research agenda in palliative care is distinct from that of the self-management of long-term illness.

Conceptual definitions

The World Health Organisation's (WHO) definition of palliative care is broad: 'an approach that improves the quality of life of patients and their families...through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain....physical, psychosocial and spiritual (WHO, 2018p1)'. The holistic reach of this definition to include psychosocial as well as spiritual elements is clear, combined with more focus on the role of family carers. It was this potential for holistic, integrated care that I explored in a multi-centre study of complementary therapies for cancer patients (Roberts *et al.*, 2013).

The European Association of Palliative Care, whilst similar, is perhaps more definitive in adding. 'Palliative care is the active, total care of patients whose



disease is not responsive to curative treatment'....(EAPC, 2018p1) The non-curative aim is important to highlight as end-of-life care is the foreseeable trajectory, whereas in chronic non-curable conditions, living with illness is possible for many years and decades. The EAPC, adds, 'palliative care affirms life and regards dying as a normal process' (EAPC, 2018p1). The ethos of palliative care therefore accepts the dying process and responds through the delivery of treatment that lessens the symptom and side effect burden on patients and their carers or families. The focus on early detection arises from the considerable evidence base that for a good death, supportive and palliative care should be started early and according to need (Fowler, 2012; NIHR Review, 2015; Drake, 2016).

### Operational definitions and Quality of Care

In practice, the point at which a person is suitable for palliative care or at the end of life stage may be unclear and practitioners may have different working definitions of what the term means for their patient. When the diagnostic and prognostic news is delivered, however, it should be done so sensitively, and an evidence based sequence of communication appears to facilitate adaptive coping, patient or family member comprehension, and practitioner ease (Maguire, 1998; Baile, 2000; Fallowfield and Jenkins, 2004). Importantly, a recent report by the Royal College of Physicians (RCP, 2018) found that early conversations about death with patients are still not happening and communication often lacks sensitivity. The research agenda is as salient now as twenty years ago.

### Improved quality of end of life care through the delivery of appropriate communication skills

My research agenda was led by the need to deliver sensitive and appropriate communication to people towards the end of life. The task of 'Breaking Bad News' is an advanced communication skill, delivered by medics with a varying degree of effectiveness (Baile, 2000). However, there was much to suggest that in reality it is an iterative process, also worked through with patients and their families within the community by District Nurses, who are untrained in communication at this level (Richardson, 2004; Schaepe, 2012). The evaluation of SAGE and THYME for use in community settings, had the potential to address these unmet communication needs, now required by the NMC (Nursing and Midwifery Council, 2015). My mixed methods pilot evaluation of SAGE and THYME showed promising potential for raising nurses' motivation to offer supportive, psychosocial care (Griffiths, Wilson, *et al.*, 2015). This has since been reinforced by eight independent reviews and trainer evaluations (Table 4b Impact Appendix). A broader, updated systematic review of CST (communication skills training) in cancer care (Moore *et al.*, 2013), including a meta-analysis of 522 nurses, found moderate

to high evidence of greater empathy and use of open questioning in intervention groups, with lower evidence of reduced anxiety after training.

#### d. Improved Outcomes in Disabling Conditions

The link between disability and illness is complex. A medical condition in itself need not be disabling and if experienced as such may be more attributable to poor access to care or disabling environments (MacLachlan and Mannan, 2013). However, many LTCs are experienced as disabilities by patients themselves. The publications relating to Guillain Barre Syndrome (Davidson *et al.*, 2009, 2010) represented a distinctive route in my research experience. The focus on a rare condition is valuable as whilst the population prevalence and incidence may be lower, the impact on patients and their family is great (UK Rare Diseases Policy Board, 2018). Guillain-Barre syndrome also represents a contrast to LTCs in terms of its distinctive disease trajectory and set of challenges to patients. It is an acute condition causing neuromuscular paralysis, generally associated with good recovery post nadir and mostly affecting vulnerable groups: children and elderly people (Davidson *et al.*, 2010). Understanding of its natural history has evolved since 1916, its characteristics vary by country and diagnostic criteria have been established in the absence of a diagnostic biomarker (Hughes, Cornblath and Willison, 2016). In assessing recovery, several constructs relating to disability are relevant: functional outcomes, mainly mobility (F-Score scale), anxiety and depression (HADS), quality of life (sf36), and fatigue (FSS; Fatigue Severity Scale), which help to determine rehabilitation need. In common with my other research, these papers focused on lower access to care i.e. physiotherapist-led rehabilitation, but did so by assessing the precision of outcome measures. The population level data suggested the F-Score should be interpreted with greater discrete validity as lingering disability; particularly fatigue was a concern in patients scoring (1) minor symptoms.

It is significant that in my sample, the median time since diagnosis was 7 years, as subsequently published work has measured outcomes at 10 years (Forsberg, Press and Holmqvist, 2012), and 20 years (Drory *et al.*, 2012), which potentially picks up greater disease outcomes over time. The Forsberg prospective study utilised different outcome measures including the EGOS (Erasmus GBS), and reported reduced mobility and fatigue at 2 and 10 years. The Drory retrospective study, also incorporated a different outcome measure ODSS (overall disability sum score), along with the F-Score and FSS, and found persistent and at times severe fatigue over the years. Overall, recent evidence has found residual disability in GBS albeit by different methodologies, that has an impact on patients' ability to perform activities of daily living and highlights a treatment need.

#### e. Secondary Prevention of disease update

There is persistent concern that the management of Diabetes and CKD requires a paradigm shift (Winocour, 2018). In terms of prevention, an observational, population level study of vascular health checks in primary care from 2009-2013 was conducted (Robson *et al.*, 2016). This screening programme of detection leading to supported behavioural change, required a target uptake of 70%; whilst considerably under target, the detection of new cases and increased statin prescription has improved treatment of coronary vascular disease (CVD) and the associated conditions of hypertension, diabetes, and CKD. Whilst encouraging, the results are based on medication alone - there is no evidence of benefits to behavioural change. Uptake is still below target so those at most risk are missed and overall the programme lacks cost effectiveness. A Cochrane Review (Dyakova *et al.*, 2016) compromised by heterogeneity between trials found that screening for CVD had no statistically significant effects on clinical outcomes, though favourable effects on CV risk factors; hypertension and cholesterol. It could well be that the longer-term benefits at the population level will be detected over time, though perhaps with more targeted intervention.

## 11. Evidence Reviews

The purpose of evidence reviews is to provide a critical review of the current state of knowledge and research in my fields.

### a. Patient Self-management and Access to Care Update

In 2012, I drew on a conceptual multi-dimensional model of access, which incorporated the constructs of Penchansky and William Thomas (1981), Szczepura (2004), and Gulliford *et al.* (2009) In Wilson *et al.*, 2012). There are also subtle developments in understanding 'access' as an issue of appropriate use of service from patient perspectives (Dixon-Woods *et al.*; In Gulliford, 2017), and using missed appointments as an indicator of vulnerability for lower access (Ellis *et al.*, 2017) (Dixon-Woods *et al.*; In Gulliford, 2017).

The research field in BCT (behavioural change interventions) to promote self-management is vast and in terms of intervention design, necessitates graphical diagrams of complex interventions (Hooper *et al.*, 2013). Earlier research has found the strongest evidence in favour of self-management on the outcome of self-efficacy (Greenhalgh, 2009). The PRISMS over-view outlined several core components of beneficial supported self-management interventions, requiring a whole systems or multi-level approach (Taylor *et al.*, 2014). Firstly, LTC education building on patients' prior knowledge and beliefs about their condition. Secondly, psychological strategies to facilitate patient adjustment. Thirdly, treatment adherence strategies. Fourthly, practical support with daily living, action plans to prevent exacerbations, intensive disease-specific training including clinical tasks. Finally, social support as a

core component. A culture of organisational support as well as adequate resourcing and cost effectiveness is a key pre-requisite to delivery at provider, systems and patient levels.

What many reviews aim to achieve is an identification of efficacious components, assessment of relative effect sizes and sub-group analysis to promote equality of access. For instance, a recent review of quality initiatives in retinopathy screening was conducted to improve attendance (Lawrenson *et al.*, 2018). On the basis of 66 trials in the US (17 with disadvantaged and ethnic minorities), all initiatives showed significant improvements in missed appointments with largest effects for goal setting initiatives in glycaemic control and risk management in those groups who had missed the most. There was insufficiently high quality evidence to judge cost-effectiveness. A further review (Malanda *et al.*, 2012) aimed to assess (SMBG) self-monitoring of blood glucose for non-insulin dependent people with diabetes type 2. Drawing on 12 trials and 3259 participants, outcomes were assessed on interventions of 6 months to 12 months. Meta-analysis found positively significant effect in HbA (1c) control at 6, though not 12 months. Initially promising indications of cost-effectiveness were compromised by higher discontinuation in intensive SM programs over time.

#### b. Personalised Care Planning

A further systematic review investigated the efficacy of personalised care planning (Coulter *et al.*, 2015), a strongly supported form of self-management in LTCs. Results were based on 10,856 participants mainly with diabetes and some various long-term conditions. Pooled data from a sub-set of trials, found moderate quality evidence in favour of personalised care planning for improved self-efficacy. There was more limited evidence on similar outcomes: improved patient activation, empowerment, perceived interpersonal support, and physical care. Overall, there was greater efficacy in using telephone support with more frequent care planning cycles and with the same clinician in integrated care.

#### c. Shared Care Interface

An issue also relating to the theme of consulting options is the potential of shared care (Smith *et al.*, 2017) between primary and secondary care. This review of 42 controlled studies and 18,859 participants drew on forty one complex interventions considered moderate to high quality. There were only slight clinically improved outcomes for hypertension, CKD and stroke, though high effect for the management of depression. The results may be limited by short follow up times, but there is no case for cost effectiveness in terms of physical health.

#### d. Digital or Tele-trials

Since my paper, there has been an expanding research agenda on telephone and computer assisted self-management. A review (Jongh, 2012) to evaluate the use of SMS and MMS (short and multimedia message services) in four RCTs including 182 participants, found no advantage in primary outcome measures compared to usual care. This included glycaemic control (HbA1c), incidence of diabetic complications, and body metrics. Improved self-efficacy and social support in association with media interventions for diabetes was only found in one study; patient amenability to the interventions was not high and health utilisation similar for control and intervention groups. A more recent review has acknowledged the lack of evidence base though broadened scope to include process measures (Lee *et al.*, 2018). In ten of twelve trials, statistically significant results for interventions were reported; these included symptom assessments, reminders, and tailored feedback. A substantial proportion of either indeterminate or high-risk bias studies were included. A current trial protocol of BetaME looks promising as this is a multi-component digital programme over 16 weeks and 36 week follow-up, including ethnic minority groups (Sarfati *et al.*, 2018).

#### e. Multi-morbidity including Mental Health

It is also important to recognise the distinctive needs of people with mental health problems and their challenges to self-care, as the risk of type 2 diabetes in these groups is doubled (Mcbain *et al.*, 2016). A recent review could find only one high quality trial in this area and results were inconclusive. Comprehensive research on patients living with multiple-morbidities is limited in general (Smith *et al.*, 2016). In this later review of 18 trials, the principle intervention design was one of case management and further MDT involvement, along with patient supported self-management. The results again were equivocal due to methodological limitations.

### 12. Introduction to Critical Reflection

In both teaching and academic research, I was trained to practice reflectively (Schön, 1987; Glaze, 2002). There is value in recognising the lived experience of research behind the publications as in reality they constitute only a small proportion of the research process itself. This is consistent with the phenomenological approach and the application of *epoche*; learning through lived experience and the suspension of judgement (Gallagher, 2012). The emphasis here, is on how my skills have been informed by experience rather than being overly biographical (du Preez, 2008).

#### a. Reflections on experience

The majority of the following research support exercises were justified to facilitate study recruitment, yet have wider benefits of forming good relationships with stakeholders and deepening understanding of patient and practitioner perspectives. Research consultation exercises with service-users are particularly unique opportunities for people with illnesses to share their thoughts outside of patient-clinician environments.

To prepare for the Guillain Barre Syndrome study and gain access to members of the support group, I visited the organiser of the Support Group at his home in Wales and spent the afternoon with him and his wife discussing the project and learning how the condition had affected them both. This strengthened our relationship and helped me understand the effects of the condition. Similarly, in researching referral and consulting options in CKD, I spent a morning with a Consultant Nephrologist at Central Manchester Foundation Trust, observing the clinic, consultations and referral processes. In planning the District Nursing Psychological Support Study, I initially spent a morning with a District Nurse on patient rounds in the community, meeting the patients and observing the challenges and rewards of the role. As part of bid development with a cardio-thoracic team in London, I further observed coronary artery bypass graft surgery (London Chest Hospital, 2013).

In addition, I have led PPI in research tasks; often-informal consultation exercises with patient groups in cancer, diabetes, COPD and migraine. These experiences have given me a level of understanding in health research that resists quantification by research output alone. As a non-clinician, the experiences lacked over-familiarity and in seeing these issues anew from social scientific perspectives, I have contributed fresh perspectives to the research fields. In parallel, there is some utility in viewing most research tasks as system 2 type reasoning, and PPI consultation with clinic observations as predominantly type 1 system characterised by fast, direct and spontaneous inter-personal responses (Sheppard *et al.*, 2018). In this way, the emphasis is on both on knowledge and how I know; with reasoning: how I think – both are artefacts of heart and head.

The greatest shift in my understanding since the ESRC Masters Training in 2002, and throughout research during 2006-2014, is the value of pragmatism in research and understanding of the pre-conditions necessary to make research happen: meeting funder requirements, having the organisational infrastructure and support, as well as collaborative partners (academic and clinic). Another is the ethical responsibility of research design (see section 9g), and applying the research imagination to understand how my work could have been done differently (Mills, 1959); for instance in the three first author papers.

b.

### c. Four Examples of Critical Reflection

#### Systematic Review

The review was conducted according to Cochrane Collaboration protocol, and using evidence appraisal tools (Cochrane Collaboration, 2018). The rationale was that this process of precise identification, evidence appraisal and synthesis would produce high quality evidence to inform policy (Alper and Haynes, 2016). Whilst I embedded critique within the synthesis, on reflection I think that both the scope and type of review could have been approached differently. There are effectively two reviews condensed into one paper. The decision to be inclusive in terms of study design meant that varying study designs were synthesised. The quality appraisal scores could only be joined by me devising a consistent scoring system. A narrative or realist review, conducted systematically would have been a more suitable approach for the complex aims of understanding self-management and access for ethnic minority groups. In conducting a scoping review, I realised that heterogeneity of outcomes would prevent a meta-analysis. At the time, the definition of systematic review was being challenged, and there have been subsequent efforts to give narrative reviews parity: the choice of review approach is ultimately dependent on the type of research question (Greenhalgh, Thorne and Malterud, 2018). I found the greatest challenge to be the methodological rigour, in planning, conducting and reporting the review. However, in evaluating material on communication barriers such as cultural differences, practitioner's use of communication styles and the impact of mechanistic communication, I developed the interest in communication skills that I later explored in palliative care.

#### Chronic Kidney Disease: Referral and Management Options.

The consulting options of telephone and computer review developed my work on patient amenability to telephone follow-up. The paper demonstrated real practical barriers to further application of NICE guidelines and referral practices based on financial concerns. In hindsight, the validity of the rating scale was questionable, as whilst interviewing I found the majority of respondents experienced difficulty in choosing an option. Whilst practitioners understandably found it difficult to relate to the concept of an 'average' patient, given they assess all individually, I found the patient's ability to answer of a different nature. There was a sense in which they felt it was not their place to imagine the delivery of service any differently than the current arrangement. Whilst this is my interpretation as the qualitative researcher conducting the interviews, it was within my role to form these impressions (Miles and Huberman, 1994). The methodological defence outlined in my paper, was that the structured exercise provoked discussion and was interpreted alongside the qualitative data. On reflection, there is a good case for

concluding that it should have been exclusively a qualitative study. A further issue was the under-recruitment of ethnic minority patients in the study which raises ethical questions given the higher proportion of South Asian people affected in Greater Manchester. The factors associated with the under-involvement of these groups in research is similar to that of reduced access in health care overall (Wendler *et al.*, 2006).

### Improved Outcomes in Guillain Barre Syndrome

This publication highlighted methodological as much as substantive issues which could have been discussed in more depth as an implication for practice. For instance, the use of generic patient reported outcomes (PROMS) rather than disease specific PROMS was largely due to a lack of GBS specific measures. As the F-Score seemed low on responsiveness, the development of patient related outcome measures in GBS by interviews could have been advocated to be more inclusive of patient perspectives. This would have increased validity of measures and been empowering for patients.

### Communication in Palliative Care

This research deepened practitioner understanding of community based palliative nursing, and also indirectly overlapped with the predictors of lower access to care discussed in my other papers. What many nurses highlighted as challenges of family-home settings, e.g. conflicts in interactions, drug dependency, anti-social behaviour, mental ill-health, deprivation, perhaps contrasts sharply with images of family support in national cancer research campaigns (Cancer Research UK, 2018). The clinical significance is that these factors not only act as barriers to effective communication – justifying the evaluation of a communication tool – but also mediate the care plan and patient's decision-making. The research also involved me applying a new methodology: a series of focus groups, which require observation of group dynamics in contrast to individual interviews. This was the most suitable approach for an exploration of shared experience and understanding amongst nurses.

On reflection, I would have developed a further publication on misunderstandings around pain administration, since there was considerable material on this area, which was condensed to only a short paragraph. There was also overwhelming feedback from the participating nurses that they felt surprised and touched to be involved in the project and dissemination event; perhaps a sign that their professional self-value was fairly low and investment in their CPD irregular. A future agenda for research is to examine the longer-term impact of training and assess their skills either in practice or simulated scenarios with actors. Quantitative assessment of communication skill is a viable alternative (Radziej *et al.*, 2017), and could be combined with qualitative feedback. Evaluating SAGE and THYME for care assistants is also



an option. It is however, harder to justify a trial design ethically given that a group will be deprived of a potentially beneficial intervention and patient outcomes as a result of the intervention will be difficult to measure.

### 13. Research Impact

The aim of this section is to demonstrate how my work has contributed to key areas and made an impact in terms of the standing of journals and the reception of the publications in citations and reviews.

#### a. Self-Management in Long-Term Conditions and Access to Care

The Systematic Review was published in a journal with respectable impact and broad remit; mainly to Public Health and Social Work audiences (Tables 4b & c). Given that the roots to barriers of ethnic minorities gaining improved access and self-management lie in socio-economic and cultural factors relating to intervention design, this broad audience target was relevant. As of February, 2019 30 citations were recorded via Research Gate (Table 4c). There has been international impact in citations from America, Australia, India, China, Uganda, Canada, Korea and Arabic speaking countries. Encouragingly, the emphasis of future work has been on marginalised groups e.g. Rural Uganda, Black Africans, South Asian men, and women in pregnancy. The paper has informed further research in stroke, heart failure, severe mental illness, tele-health trials, and up-take of allied health care, as well as a focus on the impact on carers. There have been unanticipated directions in inter-disciplinary research e.g. environmental research and smoking cessation, as well as biomedical science and engineering. The citations in high impact journals; British Medical Journal (BMJ) and BMC Medicine extend the reach to clinical audiences. The citation number (33) and overall readership via the publisher is higher and Mendeley metrics similarly suggest an international readership (Table 4d). In terms of the UK, the research was joined with other programmes in CLAHRC to inform a large scale implementation strategy (Harvey *et al.*, 2011). It has been part of a research agenda in publications on implementation science (Baker *et al.*, 2009; Lockett *et al.*, 2014) bringing the original research closer to implementation.

#### b. Improved Communication in Palliative Care

The papers relating to improved communication in palliative care received the following citations (Tables 4c & d). Firstly, Breaking Bad News about Transitions to dying, up to 24 citations (16 recorded on Research Gate). This was published in a high impact journal, ranked relatively highly for Health care, Public health and Medicine (Table 4a). It has since been cited in some appropriate high impact journals (BMC Palliative Care, British Journal of General Practice). It has also had notable presence on Twitter (71 tweets).

The general reach however, has included focus on its application to the palliative care transition, nurse perceptions of communication, individualised care planning and dignity promoting interventions.

Improving Communication with palliative care patients: An Evaluation of SAGE and THYME; 8 citations and 18 publisher recorded citations (Table 4c & d). This was published in a lower impact journal, though one more targeted to cancer nurses, and in some ways, more specific as general palliative audiences had been covered elsewhere. It has since been cited in suitable high impact journals (BMJ Supportive and Palliative Care; Palliative and Supportive Care, Cochrane Database of Systematic Reviews 2018). It has also reached practitioner levels in the Nursing Times (Connolly, 2016a and b), where its broader reach has included aspects of staff-burn out and spirituality.

A Qualitative Exploration of DNs care of patients in the home received 9 citations (Table 4d), on publisher metrics, in a lower impact journal (Table 4b). This is largely because it is a subscription only paper, rather than free access, and perhaps due to its exclusively qualitative focus, which specialises interest. It has been cited in a Scandinavian Journal applying a phenomenological approach, and a scoping study in Australia. I have also received requests for copies via Research Gate.

Perhaps a most significant departure is the work establishing that District Nurses do break bad news about transition to dying and therefore the communication challenge lies within district nursing as well as medical disciplines (Griffiths, Ewing, *et al.*, 2015). These developments in understanding the complexity of communication in community palliative care settings, provided the background research for a new agenda on how patients share bad news with others, including a proposed intervention, and wider application to patients with lung cancer (Ngwenya, Farquhar and Ewing, 2016; Ewing, G. *et.al.* 2014).

The greatest impact of the papers however is detailed in Table 4d, in terms of national and international impact to academic and clinical audiences. The clinical impact has reached national levels, and the communication tool is now taught to medical students.

#### c. Complementary Therapies in Palliative Care

This paper had significant, yet modest impact; 6 citations in a low impact journal (Tables 4-c). However, it is a specialised area, and its strongest impact was in national and international dissemination output for conferences (EAPC), and in its presentation at the House of Lords Select Committee.

#### d. Chronic Kidney Disease: Referral and Consulting Options

This paper had some impact (1 citation) in a relatively low impact journal (Tables 4c and d). It was well received at the National Primary Care Centre for Research and Development Manchester University, 2011, though primarily of methodological interest. However, there is a large impact agenda in tele-health, including apps, both innovation and evaluation, which closely relates to this publication's discussion of e-record sharing.

e. Colo-rectal Cancer Follow-up

The impact of this paper includes 19 citations and publication in a reasonably impactful journal targeted at cancer nurses (Tables 4c and d). The citations suggest impact remained in the nursing community, and extended into broader information needs, patient and carer perspectives, remote follow-up (virtual clinics), technologies, and other cohort groups, prostate cancer, post colostomy cases and metal hip surveillance. It has been cited in high impact journals including the British Journal of Nursing, and formed the basis for a current trial of nurse specialist follow-up in endometrial cancer (Beaver, 2017).

f. Hospice at Home Referrals

This paper had good impact, 15 to 20 citations, and was published in a high impact factor journal (Tables 4b – 4d). The citations suggest impact in the unequal access agenda continued, in directions of homelessness, material deprivation, and lower income, Denmark and the US. Some work involved a Marie-Curie collaboration, and others examined the impact on advanced care planning, and groups with liver disease or COPD. It has been cited in high impact journals including BMC Palliative Care, BMJ Supportive and Palliative Care, and BMJ Open. It also reached sociological audiences, and international academic and clinical audiences at conference (Table 4d).

g. Guillain-Barre Syndrome National Survey

The strongest impact as measured by journal impact factor can be seen in the European Journal of Neurology publication, which has been cited up to 12 times (Table 4c & d). Subsequent research has been eclectic including papers from biomedical, neuro-psychiatric, clinical rehabilitation, and qualitative research. The finding of enduring fatigue and impact on quality of life has been a theme in several publications including those of high impact e.g. Journal of Neurology, European Journal of Neurology. The Physiotherapy paper has similarly been cited 8 times and whilst published in a relatively lower impact journal, it is ranked high for target physiotherapist audience. Some research e.g. in Zambia, has investigated access to physiotherapy, whilst others have looked at impacts on pregnancy, therapy outcomes on motor control, mortality, quality of life and patient satisfaction. It has notably been cited in the Cochrane Database of Systematic Reviews, and has reached patient groups via the GBS Support Group.

#### h. Summary of Research Impact and Contribution to effective self-management of long-term conditions

Table 4a outlines overall research impact metrics: an examination of citations annually shows a considerable and consistent citation rate over time since publication. The Google Scholar citations (206) are higher than Research Gate (128) and Publisher records, as all on-line outputs meeting Google Scholar criteria are included rather than journal publications alone. Overall, my h-index is therefore 7 to 8 and citations continue each month. All of the research was returned as institutional output for the Research Excellence Framework, REF (2018), at the time of publication, though the impact was broader than organisational output alone (Greenhalgh, 2014). The tendency for researchers to conclude that more research is needed can invite an unjustified view that little impact has been achieved. However, not all research can or should achieve direct or immediate clinical impact. The staged approach to building impact potential, values pilot or feasibility work, and scoping as well as systematic reviews to inform trial and service design (MRC, 2000; 2006). The road to impact is therefore a more gradual one that is both resource efficient and realises that high quality evidence of effectiveness is not always a suitable aim for evaluations of complex interventions where processes as well as outcomes form research inquiry (Moore *et al.*, 2014). My publications typically fall within this developmental category. The measurement of impact is also one of interpretation. The Journal Impact factors are useful as indicators of likely impact but this depends on target audience. For instance, a paper that is read by nurses in the Nursing Standard on level 1 communication skills may arguably trigger more of an impact than the same material in a high impact medical journal or academic nursing journal. Also, the dissemination work (Rabin and Brownson, 2012) outlined in Table 4d, whilst not capturing the full extent of impact, goes a considerable way to build awareness of research findings to stakeholders and build research capacity.

#### 14. Summary

An examination of my corpus of published work has shown how they are all inter-related in several ways to produce a unified body of critical and impactful work. The distinct contributions I have made have been to bring social scientific understanding to clinically applied areas of study. In providing a critical review of the current state of knowledge and research in my chosen fields, I have shown how research findings are conditional on the methodological approaches applied – both their underlying assumptions and quality. The task of evaluating the efficacy or effectiveness of health care interventions to optimise self-management is largely one of methodological scrutiny and their real-world impact.

In terms of access to healthcare, relative inequalities persist and maybe considered socially entrenched. Whilst the concepts of access to health, disease and treatment operationalise as discourses, they have a powerful material basis: an individual or group's social identity and environment remain a strong predictor for their quality of life, quality of death, morbidity burden and mortality.

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## 16. APPENDIX

<b>4a: Research Metrics: February, 2019</b>			
<b>Research Gate</b>	RG Score: 16.68 Reads 3,314	Citations: 128	h-index: 7
<b>ORCID</b>		Citations: 98	h-index: 7
<b>Google Scholar</b>	i-10-index: 8 (no of papers with at least 10 citations)	Citations: 206	h-index: 8

<b>Table 4b. Journal Impact Factors</b>		
<b>Journal</b>	<b>Impact factor*</b>	<b>Impact areas</b>
Palliative Medicine	4.220	11/90 Health Care Sciences & Services 18/176 Public, Environmental & Occupational Health 19/155 Medicine, General & Internal Altmetric: 50 (Top 5% of all research output)
European Journal of Neurology	3.988	2016:41/194 (Clinical Neurology) 2016:66/259 (Neurosciences)
Physiotherapy	3.010	25/160 Physical Therapy, Sports Therapy and Rehabilitation
Health & Social Care in the Community	2.047	2016:47/157 (Public, Environmental & Occupational Health (Social Science)) 2016:6/42 (Social Work)
European Journal of Oncology Nursing	1.826	Cancer Nursing , Europe
Health Expectations	1.669	2016:56/90 (Health Care Sciences & Services) 2016:38/77 (Health Policy & Services) 2016:101/176 (Public, Environmental & Occupational Health) 2016:75/157 (Public, Environmental & Occupational Health (Social Science))
Cancer Nursing	1.665	Cancer Nursing,
European Journal of Integrative Medicine	0.801	Integrating complementary therapies
* The Impact Factor measures the average number of citations received in a particular year by papers published in the journal during the two preceding years. 2017 Journal Citation Reports (Clarivate Analytics, 2018)		



Table 4c. Research Gate Citation Data February 2019		
Paper Journal	No. of citations	References
<p>Patient access to healthcare services &amp; optimisation of self management for ethnic minority populations living with diabetes: a systematic review</p> <p>Health &amp; Social Care in the Community</p>	30	<p><b>1)</b> Kim, Giyeon &amp; Ford, Katy &amp; Chiriboga, David &amp; H Sorkin, Dara. (2012). Racial and Ethnic Disparities in Healthcare Use, Delayed Care, and Management of Diabetes Mellitus in Older Adults in California. <i>Journal of the American Geriatrics Society</i>. 60. 10.1111/jgs.12003.</p> <p><b>2)</b> Rutebemberwa, Elizeus &amp; K Katureebe, Sheila &amp; Gitta, Sheba &amp; Mwaka, A.D &amp; Atuyambe, Lynn. (2013). Perceptions of diabetes in rural areas of Eastern Uganda. <i>Curationis</i>. 36. E1-E7. 10.4102/curationis.v36i1.121.</p> <p><b>3)</b> Foster, Michele &amp; O'Flaherty, Martin &amp; Haynes, Michele &amp; Mitchell, Geoffrey &amp; P Haines, Terrence. (2013). Health for all? Patterns and predictors of allied health service use in Australia. <i>Australian health review : a publication of the Australian Hospital Association</i>. 37. 10.1071/AH12040. <b>4)</b> Majeed-Ariss, Rabiya &amp; Jackson, Cath &amp; Knapp, Peter &amp; Cheater, Francine. (2013). A systematic review of research into Black and ethnic minority patients' view on self-management of type 2 diabetes. <i>Health expectations : an international journal of public participation in health care and health policy</i>. 18. 10.1111/hex.12080. <b>5)</b> Glasgow, Takira &amp; Cheek, Liz &amp; Tabet, Naji. (2013). Efficacy of non-pharmacological interventions in controlling type 2 diabetes in patients of African descent: A systematic review. <i>Journal of biomedical science and engineering</i>. 6. 36-44. 10.4236/jbise.2013.65A007. <b>6)</b> Naz Khan, Farah &amp; Agne, April &amp; Buttan, Sandeep &amp; L. Cherrington, Andrea. (2013). Assessing diabetes knowledge and barriers to health services among patients with diabetes: A qualitative study in Delhi, India. <i>International Journal of Health Promotion and Education</i>. 51. 290-299. 10.1080/14635240.2013.825420. <b>7)</b> Shen, Huixia &amp; Edwards, Helen &amp; Courtney, Mary &amp; Mcdowell, Jan &amp; Wei, Juan. (2013). Barriers and facilitators to diabetes self-management: Perspectives of older community dwellers and health professionals in China. <i>International journal of nursing practice</i>. 19. 627-635. 10.1111/ijn.12114. <b>8)</b> Estacio, Emea &amp; McKinley, Robert &amp; Saidy-Khan, Sirandou &amp; Karic, Toni &amp; Clark, Linda &amp; Kurth, Judy. (2014). Health literacy: Why it matters to South Asian men with diabetes. <i>Primary health care research &amp; development</i>. 16. 1-5. 10.1017/S1463423614000152. <b>9)</b> Norris, Meriel &amp; Jones, Fiona &amp; Kilbride, Cherry &amp; Victor, Christina. (2014). Exploring the experience of facilitating self-management with minority ethnic stroke survivors: A qualitative study of therapists' perceptions. <i>Disability and rehabilitation</i>. 36. 10.3109/09638288.2014.904936. <b>10)</b> K Rose, Vanessa &amp; F Harris, Mark. (2014). Experiences of self-management support from GPs among Australian ethnically diverse diabetes patients: A qualitative study. <i>Psychology, health &amp; medicine</i>. 20. 10.1080/13548506.2014.897915. <b>11)</b> Knight, Holly &amp; Stetson, Barbara &amp; Krishnasamy, Sathya &amp; Mokshagundam, Sriprakash. (2014). Diet self-management and readiness to change in underserved adults with type 2 diabetes. <i>Primary Care Diabetes</i>.</p>

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<p>What constitutes a good recovery outcome in post-acute Guillain-Barre syndrome? Results of a national survey</p> <p>European Journal of Neurology</p>	13	<p>Schirmer, Lucas &amp; Worthington, V &amp; Solloch, U &amp; Loleit, V &amp; Grummel, Verena &amp; Lakdawala, N &amp; Grant, D &amp; Wassmuth, R &amp; H. Schmidt, A &amp; Gebhardt, F &amp; Andlauer, Till &amp; Sauter, Juergen &amp; Berthele, A &amp; P. Lunn, M &amp; Hemmer, Bernhard. (2016). Higher frequencies of HLA DQB1*05:01 and anti-glycosphingolipid antibodies in a cluster of severe Guillain-Barré syndrome. <i>Journal of Neurology</i>. 263. 1-9. 10.1007/s00415-016-8237-6. <b>(2)</b> Forsberg, Anette &amp; Widén-Holmqvist, Lotta &amp; Ahlstrom, Gerd. (2014). Balancing everyday life two years after falling ill with Guillain-Barré syndrome: A qualitative study. <i>Clinical rehabilitation</i>. 29. 10.1177/0269215514549564. <b>(3)</b> Darweesh, Sirwan &amp; Polinder, Suzanne &amp; Mulder, Maxim &amp; Baena, Cristina &amp; van Leeuwen, Nikki &amp; Franco, Oscar &amp; Jacobs, Bart &amp; Doorn, Pieter. (2014). Health-related quality of life in Guillain-Barré syndrome patients: A systematic review. <i>Journal of the peripheral nervous system : JPNS</i>. 19. 10.1111/jns5.12051. <b>(4)</b> Witsch, Jens &amp; Galldiks, Norbert &amp; Bender, Andreas &amp; Kollmar, Rainer &amp; Bösel, J &amp; Hobohm, Carsten &amp; Günther, Albrecht &amp; Schirotzek, I &amp; Fuchs, K &amp; Jüttler, E. (2013). Long-term outcome in patients with Guillain-Barré syndrome requiring mechanical ventilation. <i>Journal of neurology</i>. 260. 10.1007/s00415-012-6806-x. <b>(5)</b> Drory, Vivian &amp; Abraham, Alon &amp; Bronipolsky, T &amp; Bluvshstein, V &amp; Catz, Amiram &amp; Korczyn, Amos. (2012). 142. Occurrence of fatigue over 20years after apparent recovery from Guillain-Barré syndrome. <i>Clinical Neurophysiology</i>. 123. e57. 10.1016/j.clinph.2011.11.223. <b>(6)</b> Drory, Vivian &amp; Bronipolsky, Tanja &amp; Bluvshstein, Vadim &amp; Catz, Amiram &amp; Korczyn, Amos. (2012). Occurrence of fatigue over 20 years after recovery from Guillain-Barré syndrome. <i>Journal of the neurological sciences</i>. 316. 72-5. 10.1016/j.jns.2012.01.024. <b>(7)</b> Schapira, Anthony &amp; Hillbom, Matti. (2011). Publishing changes and information delivery in the clinical neurosciences. <i>European journal of neurology</i>. 18. 1365-72. 10.1111/j.1468-1331.2011.03594.x. <b>(8)</b> Forsberg, Anette &amp; Press, Rayomand &amp; Widén Holmqvist, Lotta. (2012). Residual disability 10years after falling ill in Guillain-Barré syndrome: A prospective follow-up study. <i>Journal of the neurological sciences</i>. 317. 74-9. 10.1016/j.jns.2012.02.026. <b>(9)</b> Adela Vigil Zulueta, Isabel &amp; Guerra Santana, Arelis &amp; Ochoa Undangarain, Lázaro &amp; Sandra Hernández Zayas, Marcia &amp; Ariel Domínguez Osorio, Carlos. (2012). Rehabilitación de niños y adolescentes con síndrome de Guillain- Barré. MEDISAN. 16. 1513-1523. <b>(10)</b> S. J. Merkies, Ingemar &amp; Faber, Catharina. (2012). Fatigue in immune-mediated neuropathies. <i>Neuromuscular Disorders</i>. 22. S203–S207. 10.1016/j.nmd.2012.10.014. <b>(11)</b> Uribarri López, M &amp; Aguilera Celorrio, L &amp; Miguel Martínez, C &amp; Yuste del Valle, S. (2013). El síndrome de Guillain Barré en la unidad de cuidados críticos en los últimos 10 años. <i>Revista Española de Anestesiología y Reanimación</i>. 60. 257–262. 10.1016/j.redar.2012.10.014. <b>(12)</b> Rajabally, Yusuf &amp; Seri, Stefano &amp; E Cavanna, Andrea. (2016). Neuropsychiatric Manifestations in Inflammatory Neuropathies: A Systematic Review. <i>Muscle &amp; nerve</i>. 54. 10.1002/mus.25112. <b>(13)</b> Sangroula, Dinesh &amp; Durrance, Richard &amp; Bhattarai, Shirshak &amp; Nandakumar, Thambirajah. (2017). Neuropsychiatric debut as a presentation of Guillain-Barré Syndrome: An atypical clinical case and literature review. <i>Journal of Clinical Neuroscience</i>. 44. 10.1016/j.jocn.2017.06.041.</p>



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Research Gate citation number recorded as lower than Publisher recorded citations see Table 4c		

<b>4d. Journal Measured Publication Impact and broader impact</b>		
<b>4c Google Scholar and Journal Measured citation number</b>	<b>Mendeley, Plum-X &amp; social media metrics</b>	<b>Broader Impact (Audience)</b>
<p>Patient access to healthcare services &amp; optimisation of self-management for ethnic minority populations living with diabetes: a systematic review Journal: Health &amp; Social Care in the Community, 2012. <b>Google Scholar 49; Journal 25 citations</b></p>	<p>Mendeley reads; Australia, Columbia, US. 26% Social Science readership; 18% Medicine &amp; Dentistry.</p>	<p><b>(Academic &amp; Clinical)</b> Used to formulate an implementation strategy (Harvey <i>et al.</i>, 2011)  Informed implementation science (Lockett <i>et al.</i>, 2014)</p>
<p>Referral &amp; management options for patients with CKD; perspectives of patients, generalists and specialists Journal: Health Expectations, 2015 <b>Google scholar 3 citation; Journal 1</b></p>	<p>Mendeley 8 reads</p>	<p>Used to formulate a UK implementation strategy (Harvey <i>et al.</i>, 2011) Used to rationalise CKD management in the Netherlands (Verwest, F. Sorel, N. Buitelaar, 2013) <b>National: Academic &amp; Clinical Oral Presentation</b> <u>National Primary Care Centre for Research &amp; Development. Manchester University, February 22<sup>nd</sup>, 2011</u> <i>An appropriateness review of referral &amp; management for patients with suspected or diagnosed chronic kidney disease.</i> Wilson, C.</p>
<p>Complementary Therapies in Cancer; Patients views on their purposes &amp; value pre and post receipt of complementary therapy – A multi-centre case study Journal: European Journal of Integrative Medicine, 2013 <b>Google Scholar 7 citations; Journal 6</b></p>	<p>PlumEx: 24 captures</p>	<p><b>International: European Association of Palliative Care (Academic &amp; Clinical)</b> <u>4<sup>th</sup> Research Forum of the European Association of Palliative Care, May 2006, Venice, Italy. 3 Posters</u> <i>Do cancer patients' expectations of complementary therapies match changes in quality of life, symptoms and functioning? 2) Comparative Views of patients, health care professionals and therapists on complementary therapies</i></p>

		<p><i>within cancer. 3) Complementary Therapies in Cancer: Patients' views on their purpose and value pre-post receipt of therapy. Wilson, C.</i></p> <p><u>10<sup>th</sup> Congress of the European Association of Palliative Care, 7-9<sup>th</sup> June, 2007. University Congress Centre ELTE, Budapest</u>  <i>Complementary Therapies in Cancer: exploring the contribution of therapy and therapist to patient care. Oral presentation. Wilson, C.</i></p> <p><b>National (Academic &amp; Therapists)</b>  <u>6<sup>th</sup> Annual Conference of the National Association of Complementary Therapies in Hospice &amp; Palliative Care, 7<sup>th</sup> Sept. 2006, Birmingham.</u></p> <p><i>A multi-centre evaluation of complementary therapy provision for patients with cancer – access, expectations and indications for therapy.</i></p> <p><b>National (House of Lords)</b>  <u>House of Lords, Select Committee, Whitehall London. 7<sup>th</sup> December, 2006.</u></p> <p><b>International Methods (Academic &amp; Nurses) Oral presentation</b>  <u>Royal College of Nursing. International Nursing Research Conference, 23<sup>rd</sup> March, 2006. York.</u>  <i>Case Study – a valuable strategy for nursing research.</i></p>
Colo-rectal cancer follow up study: Patient satisfaction & amenability to telephone after care	PlumX: 592 captures	Built capacity for the ENDCAT Trial: telephone follow-up in endometrial cancer

European Journal of Oncology Nursing, 2011 <b>Google Scholar 30 citations; Journal 13</b>		& informed the design of its nurse led telephone intervention (RCN 2016) nurse awards (Beaver, 2017)
Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK (2010) <b>Google Scholar 20 citations; Journal 7</b>	Social Media (3 Tweets) 30 Mendeley, 60% Medicine & Dentistry readership	<b>International (Academic &amp; Clinical)</b> <u>European Association for Palliative Care, 5<sup>th</sup> Research Forum, May 2008, Trondheim, Norway</u> <i>Hospice at Home: Inequalities in referrals to a Hospice at Home Service between two socio-economically distinct areas of Manchester, UK.</i> <b>National (Sociology):</b> Oral presentation British Sociological Association: Sheffield University, November 13 <sup>th</sup> , 2009. <i>End of life care: socio-economic status as a predictor of access to palliative care services.</i> Wilson, C.
a. Breaking Bad News about Transitions to Dying, 2015 <b>Google scholar 24 citations; Journal 11</b> b. Improving Communication with palliative care patients. An Evaluation of SAGE & THYME <b>Google scholar 18 citations; Journal 11</b> c. A Qualitative exploration of District Nurses Care of Patients with Advanced Cancer <b>Google scholar 9 citations; Journal 1</b>	a. Mendeley: 62 reads 35% Medicine & Dentistry; 32% Nursing & Health Social Media (71 Twitter; Facebook 5) b. PlumX 255 captures c. Mendeley; 11 reads; 1 Twitter	<b>International (Academic &amp; Clinical)</b> <u>European Association of Palliative Care, 7<sup>th</sup> World Research Congress, June 2012 Trondheim, Norway.</u> <i>Improving Psychological Support by District Nurses in Palliative Home Care: A Pilot Study of a Communication Skills Tool.</i>  Paper: Application of SAGE & THYME to Singapore; understanding cultural difference, filial piety (Martin, Costello and Griffiths, 2017) Intervention development of Sharing Bad News: Presented at conferences in Sweden, Czech Republic, Dublin, Spain 2012-2014 EAPC, British Thoracic Oncology Group, Relational Selves & Families in Medicine Conference. Several

		<p>Published abstracts and three published papers (Ewing <i>et al.</i>, 2016)(Ngwenya, Farquhar and Ewing, 2016)(G. <i>et al.</i>, 2014)(Bailey, 2014).</p> <p><b>National: (Inter-disciplinary)</b>  <u>Colloquium “The Many Meanings of ‘Quality’ in Healthcare” (Royal Society of Medicine &amp; Wellcome Trust) at Cumberland Lodge, 4th June 2013.</u>  <u>Wilson, C.</u></p> <p><i>The role of communication as an aspect of quality of care in primary and secondary care settings.</i>  UK Oncology Nurse Society Poster  (Connolly, M, 10.11.2017)</p> <p>Intervention development of Sharing Bad News: Presented at AstraZeneca sponsored event Cambridge, 2013 &amp; Marie Curie Cancer Care PC Research Conference London, 2014.</p> <p><b>Clinical Impact</b>  SAGE &amp; THYME Foundation Level workshop is currently being taught in 60 organisations, 1 in 5 of English NHS Trusts (Manchester NHS Foundation Trust, 2018), hospices and charities. Wolfson Foundation Bursaries granted to cover costs of training some staff. Annual SAGE &amp; THYME conferences Roll Out to Northern Ireland In Progress (Denise Cranston, South Eastern Health and Social Care Trust)</p>
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		<p>Over 1,000 facilitators trained; 90,000 staff trained</p> <p>8 independent reviews, including Health Education England funding of training &amp; evaluation at Northamptonshire NHS Trust.</p> <p>London Cancer Network 2016 makes the tool a pre-requisite of Level 2 training</p> <p>Shortlisted for Bionow Healthcare Project of the Year Award, 2016</p> <p>Roll out of training to medical students 2018</p> <p><b>Translational</b></p> <p>2017 Webinars: How to generate Senior Support for SAGE &amp; THYME training (Trusts)</p> <p>2016 Included in Royal Marsden Training Manual of Clinical Nursing Procedures 9<sup>th</sup> Ed.</p> <p><b>Academic</b></p> <p>Paper (Griffiths, 2017)</p> <p>Paper (Connolly <i>et al.</i>, 2014)</p> <p>Paper (Connolly, 2016)</p> <p>Book Chapter (In Cherny <i>et al.</i>, 2015)</p>
<p>Guillain-Barre Syndrome National Survey</p> <p>a. Physiotherapy, <b>Google Scholar 23 citations; Journal 8 citations</b></p> <p>b. European Journal of Neurology, 2010, <b>Google Scholar 17; Journal 12 citations</b></p>	<p>a. PlumX 428 captures</p> <p>b. 32 Mendeley readership, 50% Medicine &amp; Dentistry, 16% Nursing &amp; Health, 6% Neuroscience</p>	<p><b>Academic &amp; Clinical (see Table 4a&amp;b)</b></p> <p><b>National:</b> Findings presented to the Guillain Barre Support Group.</p>
<p>Key: 'Altmetric Attention Score for a research output provides an indicator of the amount of attention that it has received. The score is derived from an automated algorithm, and represents a weighted count of the amount of attention we've picked up for a research output.'</p> <p>PlumX captures: readership + exports/saves</p>		

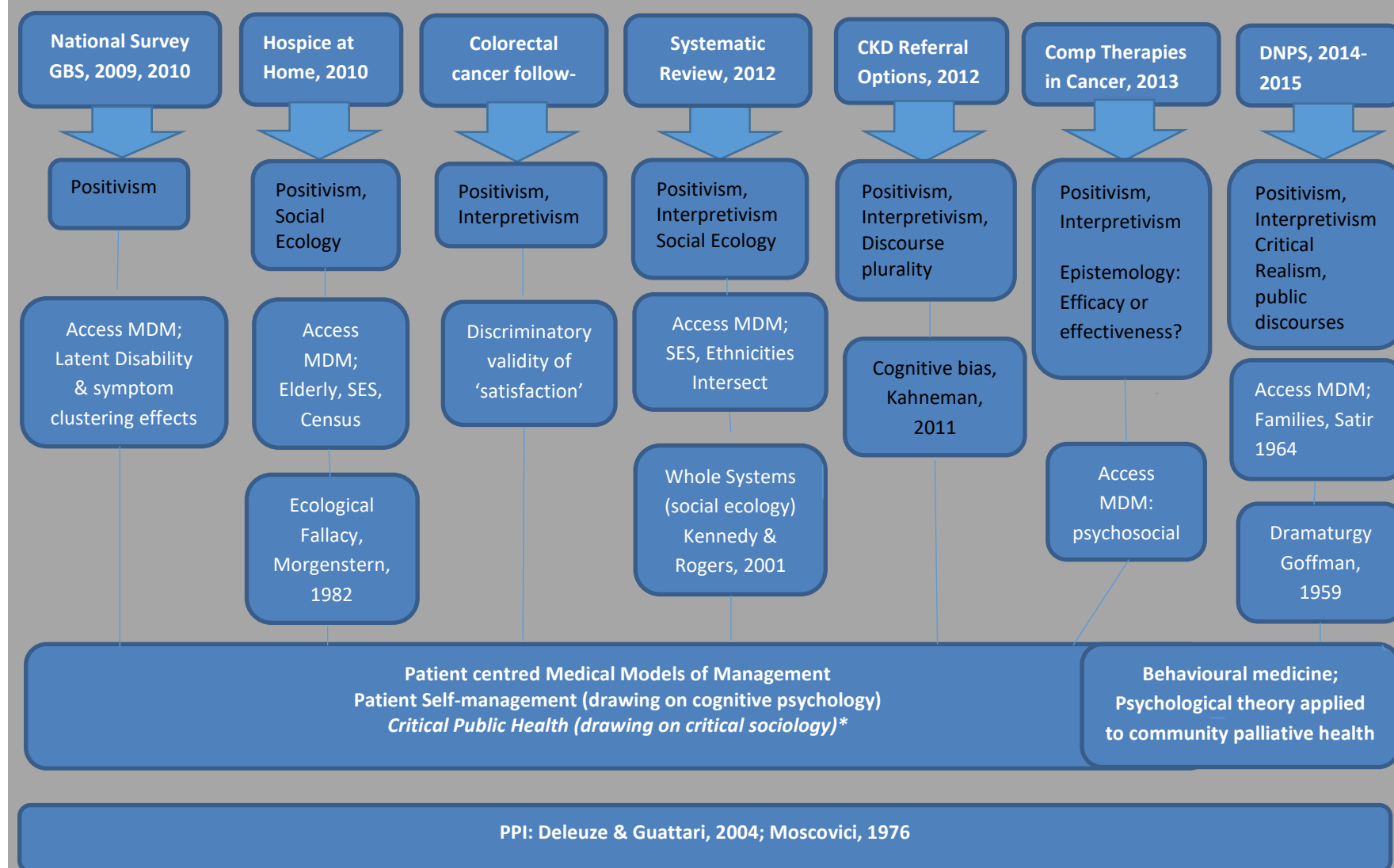
#### Table 4d: References

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doi: 10.1063/1.3033202.



Figure 3: Underpinning philosophies and conceptual developments in study publications, Wilson, C. (2019)



Key= Underpinning philosophies; SES Socio-economic status; MDM Multidimensional Model \* Greenhalgh, T. (2009)